Cybermedicine: Web-based Health Care and the Changing Physician-patient Relationship

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Web-based Health Care and the Changing Physician-patient Relationship

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Cybermedicine
Web-based Health Care and the Changing Physician-patient Relationship

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ONLY WHEN THE LAST TREE HAS DIED AND THE LAST RIVER BEEN POISONED AND THE LAST FISH BEEN CAUGHT WILL WE REALISE THAT WE CANNOT EAT MONEY.

~A Cree comment
I dedicate this—the longest paper I have ever written in my life—to my Grandfather. May I never have to know what it feels like to move to America with nothing but the shirt on my back, an old accordion, and twenty dollars balled up in a sock. His first job in this country was as an orderly in a hospital in Hartford, CT. What he experienced in the health care system then had nothing to do with what I am writing about now, but in some way I feel that the rights are owed to him. Finishing this thesis was one of the hardest things I have ever done, and if anyone ever knew what it is to work hard, it was he.

_EEC_
For anyone out there who may think we do not need doctors anymore, read this sad-but-true account of one patient who tried [unsuccessfully] to take care of himself…

“During a patient's two week follow-up appointment with his cardiologist, he informed me, his doctor, that he was having trouble with one of his medications. ‘Which one?’ I asked. ‘The patch. The nurse told me to put on a new one every six hours and now I'm running out of places to put it!’ I had him quickly undress and discovered what I hoped I wouldn't see…Yes, the man had over fifty patches on his body! Now, the instructions include removal of the old patch before applying a new one…”

~Dr. Rebecca St. Clair, Norfolk, VA
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There is one major drawback to this study. Since it takes a look at health care resources and advertising on the internet, the research naturally was done almost entirely using one of the most questionable tools available—namely, the internet itself. But I think that makes it all the better. “Pure,” if you will.

We are taught by our teachers to question anything and everything we find on a website. A person can pretend to be anyone on the internet; no one can really know for sure where information comes from or who wrote it. Therefore, it is natural to be distrustful of what is found unless it comes from an accredited site—one which we have heard of outside the web-based arena, such as *Time* or the United States Department of Health and Human Services (HHS). In light of this inherent fear of the internet, one thing seems quite paradoxical, and that is: when it comes to our health and finding health information, we suddenly throw our caution to the wind. While it is still taboo to quote a site such as “my-drugs.com” in a scientific paper, some would not think twice about ordering expensive prescription antibiotics from the same site.

Health information is quickly saturating cyberspace. It is time to stop ignoring the internet as a valid source of information and really look at what it has to offer. As health care in the United States finds itself in a state of crisis, the internet offers answers to problems in the absence of other alternatives. One could go so far as to say that people have little choice but to seek health information, medications, advice, and even organs online.
When I have given fellow students a brief synopsis of what my thesis project is about, about nine out of ten will say, “Oh, you mean like WebMD?” Yes, but WebMD is just the beginning. This common response is evidence to the growing importance of web-based health in our daily lives—mine included. I am interested in this topic not only as an aspiring physician, but also as a user of WebMD and as a health care recipient in general.

The fact that I am a young college student may offer a fresh perspective on the issue of web-based health care in two ways. First, although I have been a recipient of health care, I have been a dependent one only. Therefore, I can (conveniently) exonerate myself from all blame when talking about how the health care system got to where it is. I had no say in how it was developed, but that does not mean it is not an important issue to me now. Nevertheless, my lack of experience (and lack of bias) is akin to being thrown into the game cold. Second, growing up with the internet has offered me a similarly unique look at how health care is developing on the web. Not only is my generation more versed in computer technologies, but we have grown up with less fear of the information provided on the internet (health information included) because it is something we may need to reference every day.

This study will look specifically at some of the resources and websites related to health care, and will seek to point out some of the pros and cons of this information and its availability to the average internet-surf er. I want to give anyone who reads this a better idea of what types of things are lurking out there in Cyberspace. Whether we like it or not, such a fast-growing resource will have immense implications on the health care system. Looking at some of the possible consequences, both for patients and physicians, is important at this juncture. Eventually, it seems, we will have to find some way to integrate web-based health into the daily operation of our health care system.
I would like to thank my advisor, Dr. John Michalczyk, Chair of the Fine Arts Department at Boston College and producer of a documentary film on health care, for helping to guide me through this project—as it sought to explore somewhat-uncharted territory. His wife, Prof. Susan Michalczyk, has also been very supportive, especially during the early stages of settling on a satisfying topic. My parents deserve a good deal of thanks for their constructive criticism and for encouraging me to pursue a thesis in the first place. Lastly, I should not forget to thank my friends and roommates for their support and creative input—and for still being friends with me after months of taking the back seat to my project.
INTRODUCTION

Boiling Points

What are we to make of this in practical terms, philosophical terms, even spiritual terms? How to comprehend an age in which, suddenly, we find ourselves enmeshed in a huge information-processing system, one that seems to almost have a life of its own and to be leading us headlong into a future we can’t clearly see, yet can’t really avoid?

~Robert Wright, *Time*, 1999

In many seventh grade science classes, students might learn that if they put a frog in a pot of water at room temperature and then slowly bring it to a boil, it won’t make the slightest attempt to escape. Instead, the poor thing will sit there until every last one of its proteins is denatured, and you are left with an al dente amphibian. The reason behind this is that the frog’s nervous system cannot detect gradual changes in temperature. The damage is done before the animal realizes it is being boiled alive.

This is a rather gruesome way to start a discussion on health care, but it is also pertinent to the explanation of how the US system got to its current status. The fact that the health care system is in a state of crisis should not come as a shock to anyone. But, like a frog in a pot of boiling water, one can acknowledge the problem while society is seemingly paralyzed to do anything about it. More simply, change can happen right under one’s very nose. For those who have lived through the development of the modern health care system, it is difficult to recognize where such a system will take us until one day we were there, sitting in a pot of boiling water—with “something” needing to be done quickly.

But before going any further, a few things need clarification. First of all, this is not an essay which will identify the “something” that needs doing. The purpose here is not to solve
the problems of the health care crisis. The author is not qualified to make such an analysis. Rather, she is a lowly college student who—as graduation and the end of parental-dependence loom up in the near future—is, for the first time, confronted with what to do about her own health care during the low-income decade or two before her. The upcoming few years will be her first real experience with the problems of the health care system. Hitherto she has been covered by her parents’ insurance plan. When she needed to go to the doctor, she went. When she needed prescription drugs, she got them. Such is not the case for 45 million uninsured adults and 15 million uninsured children—which brings me to the next point I need to clarify [1].

In reference to the point above that “we” have reached the point of crisis by our own hands, there was no specification as to who “we” are. “We” are the people who are independent members of the health care system. This includes all administrators, managers, physicians, and independent patients (both insured and uninsured). It does not include dependent recipients or those who were too young have been involved much in the creation of the modern health care system. Then again, when it is said that “we” need to fix the problem, “we” refers to everyone. The internet may offer us one tool.

The internet, also referred to as Cyberspace, is a scary concept to many people—even to those of us who grew up with it—in much the same way that Outer Space was decades ago. The source of this fear is relatively self explanatory. According to Robert Wright, “the internet can unite people across distance, but it is indifferent to whether they are chess players, crusading environmentalists or neo-Nazis” [3]. But the idea of Cyberspace was not something that developed overnight. Around mid-century, theologian Pierre Teilhard de Chardin coined the term “noosphere” which he then defined as a “thinking envelope of the
earth” [3]. Perhaps what we have today is not exactly what he had in mind, but does it not fit the definition? Even earlier than Chardin, in 1932, Aldous Huxley’s *Brave New World* concludes with the horrible concept of a single-consciousness “paradise.”

Is that where we are headed? Some science-fiction nightmare? This is not meant by any means to be a doomsday rant. But one cannot deny the hold that the internet has got on our minds and bodies: “The internet and allied technologies make us neurons in a vast social brain, a brain that keeps on enticing us to make it bigger, stronger, faster” [3].

Darwin disciples would argue that the development of the internet is only a natural part of our evolution as a species. It is a “meme,” a term used to describe social characteristics that can evolve in the same way that a human gene responds to the environmental pressures of natural selection. Wright says that “the kind of social brain now taking shape has been in the cards not just since the Stone Age but since the primordial ooze; it has been, in some sense, life’s destiny” [3]. Whether or not one believes in a “direction” to human evolution, it is rather undeniable that the internet has been a long time coming.

So, having established the internet as a major contender in modern society, let us look at how it relates to the other major contender, namely the health care system. The internet, despite its imperfections, is more important to the health care system than many people might consciously think. To return to the analogy of the frog: A slow change is occurring, right under our very noses; but this time, it is technological change. We have already acknowledged that there are problems with health care, and reform is on the horizon. But humanity does not seem to want to wait. In the interim between crisis and reform, the internet has offered health care information and ideas. People have begun to turn to the
internet for solutions to their health care problems when no other alternatives are being offered.

Ian Morrison is a self-proclaimed “health care futurist” and former president of the Institute for the Future in Menlo Park, CA. He is now a consultant for health care organizations and businesses as they try to come up with a solution for the current crisis. He perhaps puts the state of affairs more eloquently:

Managed care is in disarray. It’s an industry going nowhere. They don’t have a lot of good ideas…I think they’ve bottomed out. Actually, I’ve had calls from two CEO’s in the last two months asking me to facilitate sessions concerned with fundamentally rethinking the relationship between the HMO and the provider, and the HMO and the patient. So I’m encouraged that we’ve bottomed out in some senses…The reason why managed care is important is that we don’t have another big idea. It’s not like there’s some other thing that somebody else around the world is doing…I’ve worked in 13 different countries…And there isn’t a magic bullet. Canada works for Canadians…But Canadians are not Americans; they have different values. Canadians describe themselves as unarmed Americans with health insurance. They believe in equity, we don’t. So they are different—it’s a different trend [2].

More specifically, Americans are tired of there being two kinds of prices in America today: regular prices, governed by the normal laws of supply and demand, and health care prices, governed by the arbitration of HMO’s. To get coronary bypass surgery costs $49,000. Administering Adult Growth Hormone (AGH) to a deficient child for one year costs about $20,000. A modified radical mastectomy costs $7,900. Delivering a baby by C-section is roughly $7,500. To care for a crack baby in the ICU for one day costs about $2,000 [1]. These are just a few examples of what Americans consider basic, necessary health care. They are not frivolous procedures reserved for the wealthy that any person of average income can do without. Which begs the question: What is health care in the first place? Is it a right or a
privilege? Ask a Canadian and an American and you will likely get two different answers. Again, this is not a question that will be answered here.

On a more national level, health care consumes about 13% of the GNP. Americans spend about $23,000 per second on medical care, which equals about $2 billion per day and $733 billion per year. The US Medical Bill allocated $1.3 trillion per year as of 2001, and could reach $2 trillion or higher by the end of the decade. This type of spending is taking money away from other urgent needs like education [1].

One place where money is not lacking is on the internet, the newest and increasingly more popular forum for capital investment. As Morrison argues,

   The reason the internet is a big deal is partly because of the money behind it. Why is that? Well, because we are all in our peak earning years, us baby boomers. So there’s a lot of surplus cash around…And you talk to kids. They don’t want to be investing in General Mills, you know, they want to be investing in something they think is going to be around 30 years from now. So we’re all putting money into the technology sectors [2].

To put two and two together: the health care system needs money; the internet has a surplus of money; in concert the two might mutually benefit.

One does not need rocket science to be able to understand that there needs to be a better way to provide medical care and coverage for US citizens. It does take rocket science, however, to know what that better way is. In lieu of a solution, we have the internet and the health resources it provides.

Today, about half of the population of the United States has frequent internet access [1]. Half of all those have reported using the internet for health-related queries. The development of health care information and resources on the internet—which will be referred to as eHealth—has, again, been a subtle change. This essay will look at some of the web-based resources available.
We will begin by looking at the availability of general health information and the problems associated with it. It will be of interest to look at what drives people to seek health and medical information in a place other than their local physician’s office or their local hospital, as well as the psychological effects of what they may find on the web. How they are actually searching is also being studied. The quality of this information is obviously a concern: “There are many valid uses of the internet for medical information. Still, there is a dark side—medical misinformation—that emerges because of the unregulated nature of the medium” [4]. Naturally, posting health information in such an available manner ought to carry with it some hefty regulations; as we will see, this is not always the case. The American Medical Association and other organizations are starting to work towards developing universal standards of quality, consent, honesty, and privacy, as well as establishing accountability. This portion of the essay will hopefully serve as somewhat of a navigational tool for such websites, pointing out what is good and bad regarding health queries. It will also begin a discussion of how such health information impacts the dynamic physician-patient relationship. Changes in this relationship appear to be leading us into what some call the “next generation of health care.”

Going forward from generalized health information sites, we will look at the existence of direct-to-consumer (DTC) advertising on the web. More specifically, we will deal with websites associated with the DTC sale of prescription drugs. This analysis will necessarily include a few examples of sites devoted to the sale of drugs (both with and without a prescription), as well as some of the regulations being put in place by the U.S. Food and Drug Administration (FDA) and the National Association of Boards of Pharmacy (NABP). In addition, the Canadian regulation of prescription drug sales plays an important role in
terms of how drugs are acquired in the United States. There are numerous social and economic reverberations to allowing DTC advertising.

Stemming from the discussion of DTC advertising is the idea of telemedicine, which includes anything from physician-patient email correspondence to electronic prescribing to electronic medical records. Such practices, if widely implemented, could have drastic effects (both good and bad) on the system of health care. In what is being called the “IT (information technology) decade”, administrators are working towards a massive overhaul of the health IT infrastructure.

Finally, another interesting arena within the broader issue of eHealth is the development of web-brokered transplantation, which includes both commercialized matching sites and non-profit personal sites. Many of these sites rely primarily on exciting empathetic emotions when attracting donors. Some call their effectiveness and ethicalness into question; nevertheless, they exist, and have resulted in transplantation more than once. Using this topic as a case study, we will look at the response of patients, doctors and hospitals, and regulators who claim that such websites undercut the United Network for Organ Sharing (UNOS). One could argue that the problems associated with web-brokerage stem from problems inherent to current UNOS policy.

If there is one overhauling idea to keep in mind while reading this essay, it is that eHealth (in all of the arenas mentioned above) is seeking to circumvent the physician and the failing managed care system. Whether it is to obtain a diagnosis, an organ, or a bottle of Viagra, people are using the internet to act as their own physician and their own HMO all at the same time. In other words, there has been an increase in patient autonomy. What remains a mystery is the fact that this is happening in spite of doctors being among the most respected
professionals in the work force. Why, then, are they being forced out of the health care equation? Is it a trust issue? Or are there problems inherent to the system that makes this sort of bypassing behavior imminent?

In the end, some type of conciliatory restructuring of the health care system is necessary to make it compatible with the growing patient autonomy. The internet should be made to supplement doctors, rather than replace them. Somehow, it is imperative that we integrate the new methods of eHealth with traditional methods of quality, hands-on medical care. Harnessing the power of the internet, for example, could yield a “platform for redesign of health care delivery” [2]. We will therefore conclude by looking at eHealth in the context of redesigning health care, specifically in terms of the physician-patient relationship, in the hopes that such an analysis might shed some light on where managed care is headed.
INTRODUCTION REFERENCES

1. Castro, Janice. Cover story condition: critical; Millions of Americans have no medical coverage, and costs are out of control. Here are ten ways to fix what ails us. *Time* 25 Nov 1991.


3. Wright, Robert. The Web we weave: we've had the internet in many forms over the centuries, creating a collective mind that thinks faster and faster. *Time* 31 Dec 1999.


CHAPTER 1

General Health Information and the Next Generation of Health Care

Any fool—or charlatan—with a telephone, modem, and computer can create a decent-looking website. Result: an epidemic of Internet snake oil, featuring discredited cancer “cures” like laetrile staging a comeback, $200 ‘second opinions’ with more disclaimers than a sky-diving class, and incompetent ‘diagnoses’ from self-styled ‘professors’ and ‘academicians’ at $50 or so a pop. What’s next? An e-auction site for an appendectomy or laser eye surgery?


I. Urban Legends

The preceding quote fairly accurately captures the fear associated with what will be the theme for this essay: the trend within eHealth toward the removal of the physician from the health care equation. A more extreme, irrational statement of this theme may be that, in the not-so-distant future, computers may replace doctors as the primary source of our health care; away with doctors goes any sort of human connection, and, as a result, our society as we know it comes to an end.

One is reminded of a recent television commercial that aired on several major networks involving a man on the phone with his physician (the physician is meanwhile performing surgery at a hospital) who is instructing him how to perform an appendectomy on himself at home using simple kitchen utensils. The look on the poor man’s face is priceless as he stands poised with bare stomach and butter knife in hand. “Shouldn’t you be doing this?” he says into the phone. “No, no, it’s really easy, you can do it no problem,” the doctor answers. One may not even remember what the commercial was for (most likely it had something to do with customer service) but it certainly does catch one’s attention. Although this is not an
example of web-based media, it does poke fun at the direction that many people fear eHealth is taking us: towards a how-to manual on routine operations to try at home.

Naturally, the level of concern for the consequences of eHealth is sometimes comparable to that surrounding an urban myth [18]. What do internet health information and urban myths have in common? People do not know enough about them to form rational opinions. Electronic health information is not the Boogeyman. There are some negatives to consider, and they will be looked at shortly. Anyone who has any faith whatsoever in humanity would argue that we will never go so far as to have e-auctions for an appendectomy, but one should certainly not ignore the possibility of such things. This is a trend rather than an Armageddon. We will look at just how far that trend may take us as we approach the “next generation” of health care [7].

II. Who’s Who on the Internet

The recent outgrowth of health information on the internet is not some random occurrence, but rather an expected result of significant changes in the health care industry in the past several years. These changes include the pressure to reduce costs, the penetration of managed care, rapid consolidation, intense competition, increased need for improved quality, increased government influence and involvement, and many others. These are all convenient phrases to use when talking about the health care system, but they make it easy to forget that the real problems affect real people (both patients and physicians) on an individual basis. The internet, then, offers a real resource to real people seeking real solutions—not just some ten-years-down-the-line legislation that may or not improve things for that particular person. What is most ironic is that the internet is anything but real. It is nothing but Cyberspace, and yet it is all we have got at the moment.
Before looking at some of the health information out there, it is helpful to take a step back for a moment and look at how the internet is used in general and by whom. It is probably rather self-explanatory that different people use the internet in different ways: Females tend to seek health or religious information, while males seek news, finances, sports, and politics; a large portion of African-Americans search for academic, religious, or spiritual information; young people are involved with instant messaging and downloading music, while older folks are more likely than younger ones to get health information and seek material at governmental websites. Since the year 2000, information-seeking activities have grown across the board—most by 50% or more. In general, 80% of these information seekers want to answer a specific question. According to studies done by Pew Internet’s American Life Project, “as Americans developed expectations about finding vital information on the Internet, those seeking health information online grew by 59%” [16].

In terms of health information specifically, the Pew Internet Project (one of the largest national surveys to date) estimates that 62% of internet users—some 73 million people living in the United States—search the web for health information as of 2003 [21]. Let us call these people “health seekers” [8]. Following the advent of free web access to MEDLINE via the National Library of Medicine in 1997, eHealth usage increased 1000% to 75 million searches per year, and has been increasing ever since [26]. In 2003, approximately 6 million Americans went online for health advice each day, when there were approximately 100,000 eHealth websites [20]. Health web sites are so abundant that the World Health Organization recently proposed adding “.health” to the few existing top-level domain names, like “.com” and “.org” which helps users locate sites of interest [15].
To break down health seekers’ searches into more specific categories, it is found that 93% seek information for illnesses or conditions, 65% for exercise, nutrition, or weight control, 64% for prescription drugs, and 33% for “sensitive health information” [21]. According to Rice and Katz’s *The Internet and Health Communication* (2001), the most popular disease searches appear to be: depression, allergies/sinus problems, cancer, bipolar disorder, arthritis/rheumatism, high blood pressure, migraines, anxiety disorders, heart disease, and sleep disorders. It would seem, then, that the internet is a tool for the sick rather than the healthy [8].

There are important statistics to be noted as far as gender is concerned as well. In general, women outnumber men within the total number of health seekers 53% to 47%, according to 1998 survey by Health on the Net (HON) Foundation, the third annual survey of its kind [26]. The following are data collected by Pew Internet: Women, in general, are much more likely than men to seek online health information. They are also more likely to register strong feelings about the benefits of online searches, especially those related to the wealth of information online and the convenience of online searches. In addition, women are more likely to worry about getting unreliable information [8]. Women are twice as likely to seek information for a child, but men and women are equal when it comes to seeking information for a parent or other relative. Men, in contrast, are more likely to report that their findings altered a decision when it came to their health. After seeking health information on the internet, men are more likely to ask follow-up questions to a professional after seeking health information. Men are slightly more worried about privacy issues, and also more likely to search more sensitive health topics. These are important findings to keep in mind when thinking about how searches are made and how their results affect consumers.
III. Surfing Lessons

A few pioneering studies have begun to observe how consumers are actually surfing the internet as it pertains to the quality of information obtained. One important study to look at is that of Eysenbach and Kohler, who set up a qualitative study using focus groups, usability tests, and in-depth interviews. Published in the *British Medical Journal* in March 2002, this study found that “consumers search for and appraise information in a different way than is implicitly assumed in many studies in which investigators assessed the quality of information on the web by entering a single search phrase and systematically evaluating the quality of all hits” [6]. A group of 17 participants of ages ranging from 19 to 71 were given a list of health-related questions to answer (in a maximum of 20 minutes per question) while in a usability laboratory setting, and their query processes were observed. Questions were chosen from the Heidelberg Database of Patient Questions (HEIDPAQ), an anonymous repository of questions asked to an “ask the doctor” service. Examples of such questions include “If you want to travel to Australia, do you need malaria prophylaxis?” and “What is the definition of being overweight?”[6]. No search engine or method was recommended to find these answers; participants were encouraged to think and act as they would at home. Surf Spy software was used to log all web addresses visited, while human observers took notes. Interviews were conducted immediately following the searches. The aim of these interviews was to identify the needs, expectations, and problems of consumers when searching health information on the internet, with emphasis on how consumers appraise the quality of such information [6].

Surf Spy log data showed 763 different web pages from 375 sites were visited by these participants [6]. On average, they spent only 1 minute 9 seconds on each site [6]. In the
authors’ words, “We found no correlation between internet experience and search time. In some cases, participants continued the search even after finding a page with an answer, generally because they did not understand the information encountered rather than because they did not trust the source” [6]. On that note, there were three nurses in the group who spent slightly less time per site, suggesting that it is easier for people with some medical background to more efficiently search for and assess eHealth information—a finding which is of no help to the average consumer.

A total of 280 search queries were made among the seventeen participants, who used one of eight search engines, including Google, AltaVista, Yahoo, Web.de, dr-antoniuss.de, Abacho, Lycos, and Fireball.de. Only 35% of those 280 queries consisted of more than one search term, such as “Australia malaria prophylaxis.” (The mean number of terms was 2.4.) Only one of the participants used a Boolean operator (“AND”); phrase searches in quotes were used by only 5 participants. Only 9 participants looked at search results beyond the first page (there are ten search results listed per page), and only 5 of those actually ended up clicking on a link beyond the first page. Despite these somewhat “ineffective” search strategies used, participants were very successful in retrieving information that enabled them to answer the questions in such a way that was satisfactory to them. This study did not check the correctness of these answers; it was only concerned with how they were obtained.

So, in general, participants were very successful in finding answers to health questions that they were satisfied with by trying various search terms by trial and error. They would explore the first few hits by cursory examination of the content of the page, and refine their search strategy from there. In terms of assessing quality, none of the participants clicked on a Health on the Net logo if a certain site contained one (these logos are a seal of quality that
will be discussed later). In fact, participants could correctly reproduce the name of the website of the company of the organization who stood behind the site for only 20.9% of the answers. In most cases, the reason for this failure was not that the site did not disclose such information, but that users did not pay attention to the origin of what they were reading [6].

Some of what participants reported during their interviews is quite interesting in this regard. When asked about the authority of the source they used, one participant complained, “I want to know where that information comes from. Sometimes it is hard to detect who is responsible for the content, and this is bugging me.” In regards to layout, another said: “The presentation of the site is very important, so that it appears professional.” The content itself “should appear in a language that a medical layperson can understand without great difficulties.”

In terms of how they felt about their experience with eHealth, opinions varied. Some had positive feelings:

In particular, for information retrieval the internet is really, really useful. I can easily go for a second, third, or probably fifteenth opinion about an issue and see what comes up.

Others were not so encouraged:

Remember how, what for, and by whom the internet has been developed. It has been developed by 18 year old chaps. We shouldn’t forget that these young fellows are putting up this crap without having a clue about what knowledge really means.

In general, consumers said that they enjoyed the new opportunities that the internet is opening up in order to look for alternatives to what their physician says. But, at the same time they stressed that they would always verify what they found on the web with their physician—which is encouraging to note.
This study, which is among the first of its kind, raises several important concerns about how consumers search internet health information. First, it notes that only the first few search results are usually explored. Browsers can rank results in various ways, and one should not rely on these arbitrary and unknown criteria to find a certain desired result. Second, the study found that “about us” and other such disclosure or disclaimer links are rarely read. Participants said that they based credibility on professional design and could rarely remember from which sites they got their information. However, this may be a result of the artificial environment in which the study was done and the time constraints under which the participants were placed; if they had been searching the internet at home, more time might have been spent on assessing the quality of each site, instead of just trying to find a good answer as quickly as possible. In short, the study concluded that more strictly-observational studies are needed to design and evaluate educational and technological innovations for guiding consumers to high quality health care information on the web [6].

Another important study by Robert Plovnick and colleagues (2004) looks at one possible remedy for inefficient searching by consumers. They began their research on the premise that “there is a significant mismatch between consumers’ health vocabulary and the terminology of the content” [17]. Their goal was to discover if there could be a potential benefit of providing a medical thesaurus to health seekers.

Participants for this study were recruited at Brigham and Women’s Hospital in Boston. Each was then asked to describe in detail his or her information needs to the interviewer (Dr. Plovnick), such that there was a previous understanding of exactly what kind of site content the participant was looking for. The subject was then given a laptop to search for his or her own answers. Each search query was later reformulated using a Unified Medical Language
System (UMLS) synonym, and researched. (For example, the search word “stroke” would be converted to “cerebrovascular accident.”) Reformulation was studied in two different search spaces: 1) the broad scope of a commercial search engine (Google), and 2) the more limited scope of a single consumer health information site (MedlinePlus).

Google is currently a leading search engine. It provides access to over three billion indexed web pages. “Its proprietary search algorithm ranks the relevance of web pages based in part on the number of links made to the page from other sites, and on characteristics of the page itself. The authority of referring pages is also considered in determining the rank of a page” [17]. MedlinePlus is a high-quality consumer-health site provided by the National Library of Medicine. The continuously-updated content of this noncommercial site, organized by health topic, includes information on over 600 diseases and conditions, as well as a medical encyclopedia and information on prescription drugs. Links to additional resources from the [NIH] and other trusted sources are also presented.

All original and reformulated search results were compared to a “gold standard answer” for each pair, which the researchers formulated using MDConsult and Harrison’s Online (websites geared toward medical professionals). The result pages were considered to contain the gold standard answer if any of the following was true: 1) The answer could be found by following no more than one link away from the initial result page, 2) at least 90% of the gold standard was present (in the case of symptom lists), or 3) at least one correct and pertinent fact was present (for general text about a topic).

Out of a total of 68 searches (34 in both Google and MedlinePlus), 23 returned no results containing the gold standard answer. Original consumer queries made up 9 of the 23, while the remaining 14 were reformulated queries; 19 were made in MedlinePlus, while 4 were
made in Google. Of all the original queries submitted to Google, only 1 produced no gold
classic answer. Thus, Google produced the least number of failed results for consumer
queries. MedlinePlus did actually contain the gold standard answer to 15 of the 19 failed
queries—it just did not come up on the search result list. This was also the case for all 4 of
the failed searches in Google. A total of 15 reformulated searches produced results that were
better than those for the consumer versions of the query (5 in MedlinePlus and 10 in Google);
7 were actually worse, and 14 were unchanged in quality. Thus, reformulation definitely
improved results in some cases, yet there was still a significant proportion of searches in this
study in which reformulation still was not enough to find the gold standard answer—even
when it does actually exist on a certain site!

Plovnick and colleagues came to the following conclusion:

Conducting Internet searches with reformulated consumer queries allowed us
to note qualitative trends in query reformulation with professional
terminology: it often helped to improve query performance by reducing
ambiguity and increasing distinguishing power, but sometimes reduced query
performance when the professional terms were arcane or ill-fitted. [17]

For example, searches using queries that utilized ambiguous lay terms such as “cavity,” “flat
head,” and “stroke,” were improved when replaced with professional terms (“dental caries,”
“plagiocephaly,” and “cerebrovascular accident,” respectively.) In addition, professional
terms tend to have better distinguishing power in locating medical contents (i.e., many of the
plagiocephaly pages contain the phrase “flat head,” while sites about screwdrivers or guitars
do not contain the word “plagiocephaly”). It is important to note, however, that many
medical sites do employ lay terms; they are actually geared toward original consumer
queries. If the UMLS term is arcane, finding the correct search results becomes even more
difficult: “pes” is the Metathesaurus preferred term for “foot” but one will not get much information about feet if “pes” is typed into the search box [17].

In general, there seemed to be pros and cons to using Google versus MedlinePlus. While Google produced many more sites than did MedlinePlus with biased or misleading information (“natural hormone replacement therapy” returned sites for aging “cures,” for example), there were also twice as many searches with at least one result in Google as there were in MedlinePlus. It may be concluded, then, that it was harder to find the correct information that did exist on MedlinePlus than on Google: “medical sites, though providing a more consistent quality of information, will not contain the answer for [about 21%] of consumers’ queries” [17].

IV. Quality Check

The studies just discussed were concerned with how consumers search, and how they could search better, but there is a separate question of how accurate the information is on health websites in general. The quality of web-based information is of importance both to patients and to the doctors who treat them. However, the scale of the problem of poor internet health information is still unclear, as is its impact on the public.

How is information quality measured? Another study headed by Gunther Eysenbach in 2002 reviewed all previous papers assessing health information quality on the internet. A total of 79 studies were reviewed in which authors evaluated a total of 5941 websites and 1329 web pages, reported 408 evaluation results for 86 distinct quality criteria. The overall quality criteria and methods used to evaluate websites included the following:
i. **Technical Criteria**—authorship, attribution, disclosure, currency (was the site recently updated?), speed and browser compatibility

ii. **Design**—visual presentation

iii. **Readability**—complexity/length of words and sentences (using readability or grade-level assessment formulas)

iv. **Accuracy/reliability/conventionality**—concordance with the best evidence, as checked against the literature

v. **Completeness/comprehensiveness/coverage/scope**

A group of reviewers looked at all of these previous studies and made a determination as to whether the papers’ opinion of eHealth was either positive or negative; their opinions were pooled to label the studies as generally positive, generally negative, or neutral (if opinions were conflicting). Eysenbach found that 70% of evaluated studies gave a negative assessment of the quality of eHealth information; 21.5% were neutral; 9% came to a more positive conclusion, but none of this last group used evidence-based guidelines as a criterion standard (the least rigorous studies tended to find the least quality problems).

In terms of the specific criteria categories above, the review made a few important points about the degree of completeness of eHealth Websites. Of the eight studies examined that dealt with internet health completeness, five of these found that around 90% of websites were “incomplete.” However, completeness as a requirement has questionable validity from the perspective of the user or the public health researcher. First, too much information may overburden users. Web sites may deliberately and with good reason focus on a single topic in-depth rather than aiming for comprehensiveness. Second, in contrast to printed educational material, a single web page or website is part of a universe of information: a topic not covered by one web page or site may be covered by another (perhaps linked) web page. Consumers will usually search across different websites when looking for specific health information. Mechanical comparison of elements from a guideline with elements covered by a single website without taking into account the context and purpose of the site or exploring links to other sites is of limited use. Perhaps a better approach would be to evaluate whether materials cover the topics they claim to be discussing, and if they are balanced [5].
It is also interesting to note that website inaccuracy varied depending on the type of health information it contained. Diet and nutrition sites were 45.5% and 88.9% inaccurate, respectively. Cancer site inaccuracy tended to be much less: prostate cancer 4%, breast cancer 5.1%, testicular cancer 6%, and Ewing Sarcoma 6.2%. However, enough sites have not been examined to make a statistically-significant claim that all diet/nutrition information is of lesser quality than that for cancer [5].

The perceived quality problem on the internet is not restricted to the health sector. A study investigating the quality of general scientific information online found that 10% to 34% was inaccurate, 20% to 35% was misleading, and 48% to 90% was unreferenced. Poor quality is also not restricted to the internet; studies of traditional media also report high levels of inaccurate or incomplete information (one study found 70% of health information on television to be inaccurate, misleading, or both). Therefore, it is important to consider the problems with eHealth against the backdrop of a larger generalized problem of consumer information in all media [5].

A helpful way to look at this problem is within the following framework. The individual’s risk (R) of encountering an inadequate site on the web is a function of both the proportion of inadequate information on the web (P) and the inability (I) of the individual (or his tools) to filter inadequate sites. Since studies usually report R but not I, we cannot infer P [5].

In closing, Eysenbach argues that instead of getting bogged down by the question of how much information is inaccurate, we should analyze where and why gaps exist between evidence-based medicine and health information on the internet, which may elicit a wealth of valuable data that may inform priorities for research, health communication, and education.
There is a lot of qualitative potential to be harnessed in a resource like the internet—but only once certain regulatory measures are taken [5].

V. The Initial Response

In the words of Thomas Jefferson, “those who desire to give up freedom in order to gain security will not have, nor do they deserve, either one.” This wisdom can be effectively applied to the internet in that many people question the sacrifice of freedom of speech on the web in return for tighter restrictions. Similarly, some would argue that regulation is not the answer when it comes to eHealth quality. Impicciatore and colleagues researched web site advice on fever in children and “concluded that it varied widely in terms of accuracy, completeness, and consistency…With at least 80 studies reporting similar findings, we need no more convincing evidence that the quality of information on the web varies as widely as it does in other media” [18]. Tom Standage blames the “hype, skepticism, and bewilderment” on human nature rather than technology [18]. Either way, it is probably safe to say that how one looks at the quality of internet health information and its potential as a resource depends on how optimistic or pessimistic one is. Optimists would argue that the internet is just the latest step in the evolution of communication, and that just like the telegraph, it will “eventually settle into a useful role in communication, before being rendered obsolete by newer technologies such as the telephone” [18]. Pessimists would argue, conversely, that the internet can never really be regulated, because human nature will always find a way to circumvent any and all constraints.

Regardless of which outlook is more realistic, several measures are being taken thus far to try to control and standardize some of what is being posted on health websites. Tools to help consumers evaluate eHealth exist in several forms. First, there are Codes of Conduct,
which are a set of quality criteria that provide a list of recommendations for the development and content of the site. These Codes are subscribed to by websites that wish to be of the highest quality. Two of the biggest examples of these Codes are 1) the eHealth Code of Ethics, developed by the Internet Health Coalition, and 2) the Guidelines for American Medical Association (AMA) [Health] Web Sites. The eHealth Code of Ethics is a document whose goal is “to ensure that people worldwide can confidently and with full understanding of known risks realize the potential of the internet in managing their own health and the health of those in their care” [4]. It defines “health information” as information for “staying well and managing disease, and making other decisions related to health and health care” [4]. It is divided into the following sections:

i. *Candor*: disclose information that if known by the consumers would likely affect consumers’ understanding or use of the site or purchase or use of a product or service

ii. *Honesty*: be truthful and not deceptive

iii. *Quality*: Provide health information that is accurate, easy to understand, and up to date

iv. *Informed consent*: respect users’ right to determine whether or how their personal data may be collected, used, or shared

v. *Privacy*: respect the obligation to protect users’ privacy

vi. *Professionalism*: respect fundamental ethical obligations to patients and clients and inform and educate patients and clients about the limitations of online health care

vii. *Responsible partnering*: ensure that organizations and sites with which they affiliate are trustworthy

viii. *Accountability*: provide meaningful opportunity for users to give feedback to the site to monitor their compliance with the eHealth Code of Ethics[4]

It is clear from the above items that the eHealth Code is somewhat vague. There are, of course, more details in the document itself, but to what extent a particular web site takes these recommendations is up to the discretion of the site’s manager.
The AMA Guidelines are somewhat more specific, and “address the creation and updating of content, acquisition and posting of advertising, the preservation of privacy and confidentiality, and the provision of reliable and efficient e-commerce” [1]. The complete document can be found at [www.amassn.org/about/guidelines](http://www.amassn.org/about/guidelines) but I have attempted to summarize the fundamental principles below:

a. authorship must be posted  
b. attribution must be available  
c. disclosure must be evident  
d. editorial content must be current  
e. quality assurance must be explicit  
f. advertising must be identifiable and separate from editorial content  
g. privacy and confidentiality policies must be explicit and adhered to, such as a link to the policy provided on the home page; all personal information should be given with informed consent  
h. e-commerce must function efficiently and securely[24]

The second form of quality measurement is by a quality label, which is a self-applied commitment by a site provider to implement or adhere to a code of conduct; the label can be displayed only after submission of a formal application and commitment to the principles. The site must also then be checked by the label provider [18]. Health on the Net Foundation (HON) produces the oldest and perhaps best known quality label, which is currently used on more than 3000 websites. Created in 1995, HON is a Swiss organization whose “mission is to guide lay persons or non-medical users and medical practitioners to useful and reliable online medical and health information. HON provides leadership in setting ethical standards for web site developers” [12]. The HON logo will usually appear at the bottom of the home page of any reputable health information site (See Figure 1.1, p. 26). Hi-Ethics also produces a label, but one which is geared toward commercial sites.
User guidance systems are a third way to measure quality. They enable users to check if a site and its contents comply with certain standards by assessing a series of questions from a displayed logo. DISCERN is a brief questionnaire to help users validate info on treatment choices (www.discern.org.uk).

Filtering tools are a fourth option. These are manually- or automatically-applied functions that will accept or deny sites and information based on preset criteria [18]. OMNI, for example, is a filter “designed for students, researchers, academics, and practitioners in the health and medical sciences” (www.biome.ac.uk/guidelines/eval/factors). One of the downsides with filters like OMNI, however, is that they tend to be somewhat costly. Third party quality/accreditation labels also come for a fee. MEDCERTAIN is one example which is being tried out in Europe. URAC is another new web site accreditation program which recently began processing applications for year-long labels.

Amidst all of these various quality measures, it is important to note that no organization or label has the capacity to identify objectively what is good or bad information. “Quality remains an inherently subjective assessment, which depends on the type of information needed, the type of information searched for, and the particular qualities and prejudices of the consumer” [18]. Some would argue that consumers must learn to deal with quality uncertainty on the internet in the same way they have dealt with it in other arenas—by learning to make informed choices about what they read and apply. Even with all kinds of
rating instruments in place, people may not have the time, energy or inclination to use the tools appropriately [18]. There have been suggestions made as to implementing automatic filters against any sites that do not conform to ethical standards, but that would only pose the following questions: Who gets to decide what is ethical or not? And, is it not an exercise of one’s freedom of speech to post whatever one wants on one’s own website?

VI. Changed Behaviors

What do real people say about eHealth quality issues aside? According to the Pew Internet and American Life Project, consumer behavior has changed as a result of eHealth. According to a recent survey, 48% say the web has improved the way they take care of themselves; 55% say it has improved the way they get medical and health information; 92% say the information they found was useful; 81% say they learned something new; and 47% say the information affected decisions regarding their own treatment and care[8].

Another series of surveys conducted by Tracy Bessel gives a more specific look at how consumers being influenced by eHealth. One survey shows that 52% of smokers and 43% of heavy smokers have quit 12 months after enrolling in an online cessation program. Another shows positive outcomes for an intervention group on female body image and physical activity. Yet another shows that “internet-based intervention provided increased social support, decreased social anxiety and improved attitudes toward surgery” [2].

In terms of saving time and money, a 1995 survey of users of AOL’s Better Health & Medical Network reported that 6% of those questioned said they were able to avoid a visit to the emergency room because of information from the site, and 26% said it saved them from at least one doctor visit [20]. And that was ten years ago. In a 1998 survey of more than 1000 California residents, those with internet access were less likely than were those without
access to report consulting their physicians and health care providers for information about medical conditions [21].

These are all promising results. However, most studies were not rigorous enough to determine the outcome for popular use of eHealth; more research is needed on consumers’ subsequent actions. “Well-designed controlled studies, instead of anecdotes and opinions, about the risks and benefits of using the internet are urgently needed” [2].

VII. The Digital Divide

In looking at the bright side of eHealth, one tends to make a major assumption: that all consumers have regular access to a computer. In spite of the promise of computer-based and computer-mediated medical information and communication, it is still true that people with preventable health problems and those who have little or no health insurance are also those least likely to have access to the necessary technologies. “A wide variety of barriers exist, such as cost, location, illiteracy, physical ability, and capacity. Public and governmental efforts are needed to reduce the gap between health information ‘haves’ and ‘have-nots’” [26]. Internet use is associated with being “younger, more affluent, and better educated” [2]. In short, we are talking about the “3 C’s”—cash, college, and computers—that separate people who are likely to make use of eHealth from those who are not [26]. Some have referred to this phenomenon as the “Digital Divide” or the “knowledge-gap hypothesis” [26]. When all is said and done, we end up with an analogous problem to the one we already have: The insured are getting a disproportionate amount of the best care in hospitals; those same people are also more likely to have a computer at home with which to access eHealth. So by posting health information on the internet, are we really bringing health care to the people?
Or, are we doing more harm than good by bringing more of it to the people who already have sufficient care?

There is some preliminary evidence, however, that the Digital Divide may be closing up. A study by June Forkner-Dunn found that from August 2000-July 2001, the number of African Americans using the internet grew nearly 20%. Nonetheless, the proportion of wired African Americans (43%) remains low in comparison with the average of online Americans (58%) [7]. Internet access among Hispanics in the United States increased by 25% from March 2000 through February 2001, indicating that more than half of that population is now online. Like African Americans, however, Hispanics have less access to cyberspace than Caucasians. Meanwhile, Asian Americans use the internet more than other group; more than 75% of that population has internet access [7].

Forkner-Dunn shows that economics play a part in access as well. “Thirty-seven percent of those who are not wired have family incomes under $30,000, whereas only 18% of those with Internet access have incomes under $30,000. Poor reading skills add even more barriers to those economically disadvantaged for accessing the world of the web” [7].

The senior population has been slower than other age groups in embracing the internet but this is changing. A Pew report [8] predicts that with many baby boomers approaching retirement age, seniors' use of the internet will increase dramatically. “The health care industry must be prepared to accommodate this growing segment of the population, many of whom will become homebound but will still need services, training, and reinforcement of medical self-management, as well as continued connection to clinicians and contact with other patients” [7].
VIII. Cyberchondria and Associated Issues

Another current problem with eHealth has nothing to do with its quality, scope, or availability but rather with its psychological affect on consumers. Cyberchondria, also known as “internet print-out syndrome” occurs when consumers misdiagnose their symptoms or stumble across quack cures, or when they begin to believe that they have all of the various disorders that they discover during their internet query [3]. Hypochondria is a well known phenomena, one which many doctors have encountered and few have taken seriously as a legitimate psychological disorder. Cyberchondria—hypochondria stemming from internet use specifically—has become widely more common in past years. It is a problem for the general practitioner simply for the time it takes up. “Hypochondriacs [and cyberchondriacs] don’t just harm themselves; they clog the whole health-care system. Although they account for only about 6% if the patients who visit doctors every year, they tend to burden their physicians with frequent visits that take up inordinate amounts of time. According to one estimate, hypochondria causes some $20 billion in wasted medical resources in the US alone” [3]. Physicians blame the internet alone for the rising numbers of hypochondriacs. Few realize, however, that these are the same people who are prone to such worry in the first place; their fear is merely fuelled by volumes of easily-accessible material available on the internet [3]. Instead of just placing blame on one source or another, physicians must stage a more pre-emptive strike on hypochondria by guiding patients to the most reputable sites. This, in turn, would require that physicians themselves become more computer literate.

In 1985, Covell and colleagues documented the obstacles physicians face using books and print media as sources of information in practice. It is now “thirteen years later, [and] there are 9.2 million MEDLINE citations with approximately 31,000 more added each
Compounding this problem, changes in health care delivery require practitioners to make more important and complex decisions in less time” [14]. This failure to use current health care evidence and technology in the practice of medicine has been termed “avoidable ignorance” by some [14]. But for physicians who are spread too thin as it is, actually avoiding this ignorance and incorporating the internet into their repertoire might be easier said than done.

The sheer volume of health information is a problem for patients as well as physicians. There is the possibility of patients getting bogged down by what they find—so much so that they begin to question their doctor’s credibility as a source of medical know-how. They may even demand to make their own medical decisions. Some may look at statistical possibilities of certain disorders and diseases and take cyberchondria to the other extreme, to the point where unwise decisions are made with a “that-cannot-happen-to-me” mindset. One study of Web searches for the term “vaccination” found that 43% led to sites advising people not to get vaccines. That is not necessarily sound advice [10]. What doctors can bring to the table as far as decision-making is concerned is sometimes undervalued. After all, “there’s a difference between having well-developed knowledge about a medical issues and just having loads of information—especially if much of that information is wrong” [10]. Patient health needs to become more of a partnership between them and their physician—something which will hopefully become the norm in the Next Generation of Health Care.

IX. The Next Generation in Health Care: A Changed Physician-patient Relationship?

One of the more eloquent descriptions of the changing patient-physician relationship is in a book entitled *Complications: A Surgeon's Notes on an Imperfect Science* by Dr. Atul
Gawande, a gastrointestinal surgeon at Brigham and Women’s Hospital in Boston. In his chapter entitled “Whose Body is it Anyway?” Gawande traces the growth of patient autonomy starting with a paternalistic era of medicine and ending in the opposite extreme. A particularly pertinent excerpt is included here:

Little more than a decade ago, doctors made the decisions; patients did what they were told. Doctors did not consult patients about their desires and priorities, and routinely withheld information—sometimes crucial information, such as what drugs they were on, what treatments they were being given, and what their diagnosis was. Patients were even forbidden to look at their own medical records: it wasn’t their property, doctors said. They were regarded as children: too fragile and simple-minded to handle the truth, let alone make decisions. And they suffered for it. People were put on machines, given drugs, and subjected to operations they would not have chosen. And they missed out on treatments that they might have preferred…One of the reasons for this dramatic shift in how decisions are made in medicine was in a 1984 book, *The Silent World of Doctor and Patient*, by a Yale doctor and ethicist named Jay Katz. It was a devastating critique of traditional medical decision-making, and it had wide influence…Eventually, medical schools came around to Katz’s position. By the time I attended, in the early 1990’s, we were taught to see patients as autonomous decision makers. “You work for them,” I was often reminded. There are still many old-school doctors who try to dictate things from on high, but they are finding that patients won’t put up with that anymore. Most doctors, taking seriously the idea that patients should control their own fates, lay out the options and the risks involved. A few even refuse to make recommendations, for fear of improperly influencing patients. Patients ask questions, look up information on the internet, seek second opinions. And they decide [25].

While only a handful of patients actively challenge medical authority using information they acquire on the internet [11], some are beginning to see the internet and eHealth as a “weapon of the weak” in situations where one party (the patient) lacks power relative to another (the physician) [11]. In reality, very few patient-controlled outcomes are being seen. Patients are doing what their doctors want them to do, either because they are being adequately persuaded or because they want their doctors to be the ones to decide. But there is
the fear that doctors are dismissing eHealth information out of defensiveness, even if such information might be helpful to a particular patient.

The problem runs deeper than that, however. A 1997 study by Harris and Associates found that “patients say that physicians don’t listen well and provide difficult-to-understand explanations. Consequences of these problems include patients’ avoiding seeing their doctors” [20]. On the other hand, physicians say that patients withhold important information, don’t follow medical directions, and so on. Forty-eight percent of physicians thought that not having enough time to go to a doctor’s office was a “very” or “somewhat” major reason that patients don’t ask questions or talk about health problems, while 67% said that not having enough time to spend with patients was a “very” or “somewhat” serious problem in their practices. Indeed, the reasons that patients turned to other sources for health information included easier or quicker accessibility (52%), not wanting to “waste” the doctor’s time (14%), and feeling more comfortable (11%) [20].

What will hopefully come out the broader discussion of eHealth will be several improvements in doctor-patient communication, at the very least. There needs to be reduced anxiety, reduced time and cost in obtaining health information, a population of better-informed patients, better discussion of sensitive topics, and increased interaction and intimacy between doctors and patients overall [20]. In fact, 93% of doctors said that better communication with patients would result in better care overall; 61% said they did not receive adequate communications training in medical school.

Relationships between patients and internet-savvy practitioners can have one of three possible outcomes when eHealth is added to the mix. First, bringing a deluge of eHealth information to the table can confuse the health issues of a patient, causing increased
physician authority—simply out of necessity—when decisions need to be made. Second, physicians can make “internet prescriptions” in which they guide patients to “approved” sites that will help to enforce their professional opinion. In effect, the patient will feel that he or she has played a larger part in deciding what to do, while in reality they have been carefully led to that conclusion. This may not necessarily be a bad thing. And third, physicians could, in the long term, become processors of information rather than providers of information. This last possibility upholds the view that “relationships will be transformed” by eHealth [11].

Either way, we are now entering the era of the “impatient patient” who wants better health care and wants it now [7]. Patients are helping to educate their physicians about research and treatments whether their physicians like it or not. But what some patients easily forget is that “rights” in terms of patient autonomy carry “responsibilities” [13]. While many commentators in the consumer health-information and consumer health-informatics fields may believe that increased consumer/patient responsibility is the way forward, some patients are clearly not yet convinced [13]. For every patient that may be questioning his physician’s medical authority, there are two patients that still “turn to their PCPs first and foremost” [11]. For every physician who wants to dictate care to his patients, there is another who is reluctant to take on such a role. When the eHealth dust settles, there will hopefully be a happy medium between these two extremes:

Claims from policy sources, academic researchers, and patients themselves are that the increase in the use of the internet for health information will result in positive shifts towards more equitable, or even patient-controlled, relationships between practitioners and patients [11].

Although online intervention may empower patients and may positively affect the patient-physician relationship, a realistic observation is that the internet will be widely
adopted as a part of usual care only if this venue improves patient self-management, betters patient satisfaction, and enhances health outcomes [7]. Online support groups are one such venue for integration. A study by McKay et al found that patients who participated in an online diabetes education and support group lowered their blood glucose levels more than controls did. Studies of online support groups for cystic fibrosis patients, amyotrophic lateral sclerosis (ALS) patients, and single mother also showed that participants in these online support groups gained satisfaction and confidence in managing their medical condition [7]. These are things that can help doctors do their job better.

When all is said and done, the symbolic power of the internet is undeniable. Acknowledging that eHealth is a powerful tool, whether for good or ill, is an important first step. Though slow to change, many patients and practitioners feel that they ought to be getting online, regardless of the potential for negative effects, just because it is such an important resource. Not being “internet-savvy” is something to be embarrassed about in this day and age [11].
9. Gorman, Christine. The web docs: The internet can fill the gaps in your medical knowledge. But you need to know how to separate the good sites from the bad. *Time* 3 Apr 2000.
CHAPTER 2

Direct-to-Consumer Advertising and Online Pharmacies

The evolution from passive patients to empowered end-users who are active participants in their health care [will come] through interactions with internet-based resources. Ultimately, it seems likely that the market will decide.

~G. Purcell, BMJ, 2002

I. An Era of Self-Medication

Another major part of the health care system and all of its problems has to do with medications—specifically, prescription ones—and how they are obtained by patients. The internet comes to play here as well—perhaps due to a more economic impetus (whereas many argue that health information websites have developed for convenience sake). More and more patients are beginning to order their prescriptions from online pharmacies, both reputable ones and some more questionable sites. They have begun to do so largely because of Direct-to-Consumer (DTC) advertising, which (via both broadcast and web-based media) brings knowledge of prescription drugs directly to consumers—naturally, along with some biases about their effectiveness. Given the growing number of domestic and foreign pharmacies that market and distribute prescription drugs without a conventional prescription, this is yet another example of how the internet is helping consumers to bypass the physician.

Case in point: A 52-year-old Illinois man with episodes of chest pain and a family history of heart disease died of a heart attack in March 1999 after buying the impotence drug Viagra from an online source that required only answers to a questionnaire to qualify him for the prescription. Though there is no proof linking the man’s death to the drug, FDA officials say that a traditional doctor-patient relationship, along with a physical examination, may have
uncovered this man’s health problems (heart disease) and could have ensured that better treatments were prescribed [6].

There are many more tragic stories like this, and there promises to be many more if prescription drug prices stay at such a high level. Thus, proponents of online pharmacies applaud their ability to provide drugs at more reasonable prices. But even these economic upsides may have detrimental effects in the long run if internet pharmacies promise to have a significant impact on the way patients are medicated.

II. The Economic Impetus

What we already know is that drug therapy is costly, with or without the internet. In fact, costs are rising faster than in any other segment of health care. In 1998, Americans spent about $94 billion on prescription drugs; in 1997, they spent $16.6 billion on nonprescription drugs and an estimated $27 billion on alternative and complementary medicines for a total of $137.6 billion [4]. With this much money floating around, it is seemingly inevitable that websites will spring up that are trying to extract their share.

In 1991, pharmaceutical companies spent $55 million on DTC advertising for their prescription drugs. By 1999, that number had climbed to $1.8 billion. In 2000, it was $2.6 billion, and has continued to grow since [10]. All of this spending suggests that DTC ads must be paying off [10]. Prescription drug sales in the US did see an 84% increase over the five-year period from 1993 to 1998, with the following four categories of drugs being the most responsible: oral antihistamines for allergies, antidepressants cholesterol-lowering drugs, and ulcer treatments [10]. These categories include 7 of the 10 drugs most heavily advertised to the public in 1998 [10]. Overall, that means DTC advertising could have added more than $13 billion to the US drug bill in 1998. Furthermore, in 1999, two-thirds of the
increase in spending on prescription drugs in the US was for the 25 drugs with the “most intensive DTC advertising campaigns” [10].

III. Physicians’ Response to DTC Advertising

DTC advertising “might or might not represent medical need, good therapy, or effective use of scarce health care dollars” [4]. How, then, do physicians feel about it? Preliminary results of a Food and Drug Administration (FDA) survey from 2004 suggests that most doctors believe that “ads help people more than hurt them” [9]. However, DTC ads are only “one of many factors that affect [these doctors’] medical practices and their interactions with patients” [9]. It was about 15 years ago that patients started playing a more active role in their own health care due to a new outlook on patient care. Formerly, as was eloquently described by Dr. Gawande, a paternalistic system of care had made the physician dominant to the patient; physicians authoritatively dictated treatment to patients rather than discussing treatment options. The radical notion that a patient’s body is his own not only altered the patient-physician relationship in the clinical setting, but in the pharmaceutical setting as well. Thus, as patients were gaining more autonomy, they began to look more and more like a tasty honey glazed ham to a hungry wolf. What big eyes the pharmaceutical companies had for a population who wanted to open the door to them, who wanted to have a say in which chemicals they are taking into their body.

Beginning in the early 1990s, manufacturers of prescription drugs began to produce ads targeted to these ready consumers in no small way. Doctors, in the meantime, had to learn how to react to patients coming in with more questions about possible drug therapies. Of the 500 doctors surveyed in 2004, 58% “agreed strongly that DTC ads make the drugs seem better than they really are” [9]. Thus, many patients went to see their doctors with high hopes
about a therapy only to be given a reality check. On the other hand, many doctors also
reported that patients came to their check-up with more thoughtful questions because of their
exposure to DTC ads. For example, 88% of the time patients did have a condition that the
drug would treat; thus, they were getting the right information out of the ad [9]. However,
one negative effect of DTC on the physicians’ end was the pressure some felt to prescribe
drugs when ads were mentioned, even though they might have questioned the effectiveness
of doing so [9]. Often, drugs are not yet on the market. Furthermore, 8% felt pressured to
prescribe a brand name if it was asked for. But, overall, the doctors surveyed did feel that
more useful discussions did result with their patients, so long as these patients understood the
necessity of consulting their physician about a drug [9]. Patients can become more involved
in their own health care, but still need their doctors to provide added information to DTC ads,
such as the reality about a drug’s effectiveness.

IV. Patient Response to DTC Advertising

In a 2004 Wall Street Journal survey of a general population of adults who go online,
61% said that buying drugs online is much more dangerous or somewhat more dangerous
than buying them from a pharmacy [15]. This is somewhat contradictory in the face of data
which estimates that approximately six million people have purchases drugs from internet
pharmacies. Web-based drug sources are a natural place for people who have been influenced
by DTC drug ads to go looking for their drugs because they are allegedly cheaper.

Of those adults surveyed by the Wall Street Journal who had bought drugs online, 70%
had gotten the same drug from a pharmacy in the past, with a prescription of course. A more
troublesome 30% were obtaining a new drug online, one for which they did not have a
prescription. Overall, 10% of online buyers were less satisfied with their purchase than with
drugs from a traditional pharmacy; 56% were equally satisfied, and 34% were actually more satisfied. The drugs they bought most often were Lipitor, Viagra, and Celebrex.

On a side note, Celebrex (made by Pfizer) is in the same drug class as Vioxx (made by Merck), a drug which was recently taken off the market for its association with increased risk of heart attack and stroke. Both drugs are cox-2 inhibitors, prescribed for arthritis and other such pain ailments. Although Celebrex most likely has some of the same risks as Vioxx, Pfizer has no plans to remove the drug from the market, arguing that safety problems with Celebrex may only apply to high dosages (400-800 mg/day) [1]. Clearly, people with heart disease would do well to avoid the drug. But with internet pharmacies willing to sell Celebrex without a prescription, patients unsuspecting of their own heart disease may be in danger—especially without a physician to specify the correct dosage. Such worries seem to be secondary to Pfizer, with Celebrex being the most-prescribed (and advertised) drug for treating arthritis. From January through September 2004, world-wide sales of Celebrex more than doubled from the same period a year earlier to $2.29 billion, accounting for 6% of Pfizer’s total sales of $37.59 billion [1]. Meanwhile, Merck has been in the midst of a financial and public relations disaster following the withdrawal of Vioxx, in part because it has been accused of muzzling news about the drug’s side effects. Its legal liabilities are estimated at up to $18 billion, and its shares have dropped by nearly one-third since the recall announcement was made in late September [1]. Pfizer clearly wants to avoid such a situation at all cost. Hopefully that cost does not include consumer health, if Celebrex remains among the top internet sellers.

There is a whole laundry list of concerns from the patient’s perspective when it comes to DTC advertising. First and foremost, it drives up prescription drug costs; advertising costs
money, and people will be willing to pay more if this advertising can convince them that they absolutely need the drug. The ads are also not objective, their main going being to increase sales rather than make people healthy. Even when used properly, prescription drugs can cause serious side effects, such as those associated with Celebrex. Therefore, prescription drugs are not like other consumable goods in that it is essential to have a doctor’s opinion before consuming them. Mintzes and Baraldi have gone on to argue that people who need certain drugs—i.e., those that may be very ill—are more vulnerable to making poor choices about their health care because they are in a state of pain or suffering [10]. New drugs are also not necessarily that much safer or more effective than old ones, but they are usually more costly due to research and development overhead. In addition, little may be known about their long term effects, despite FDA approval. There is no statistical evidence as yet that DTC ads help people make better choices or that public health will benefit [10]. Doctors, too, can be negatively swayed by DTC ads which are often a more accessible information source about the drugs they market than many more independent/reputable/current research studies on the same drugs. In light of these negative angles to DTC ads, online purchasing of drugs has become a dangerous form of patient autonomy. The important point to remember is that the problem begins with DTC ads and not with online pharmacies alone; after all, a patient can just as easily lie in person or on the phone to his physician as he can on the internet. Thus, a “diagnosis” form provided by a “disreputable” pharmacy sites is perhaps no less accurate than a physician’s notes for an uncooperative patient. In other words, if a patient really wants a certain drug, he or she can probably get it without too much trouble.

There are also, however, a few important benefits to DTC ads and online pharmacies that should be noted. Patients enjoy the ease of comparative shopping as they seek to find the best
prices [6]. The greater availability of products and an increased availability are also sometimes a factor. In addition, more than a few patients have noted the “serious frustrations” associated with a visit to the local pharmacy [8]. These include: “long waits for their medications, not seeing a pharmacist, [and] not being able to have their questions answered” [8]. If patients don’t get the direct contact they desire at the community level, the internet becomes a convenient resource for them [8]. It is also an attractive idea to those patients with difficult issues or embarrassing medications who would rather remain anonymous.

V. The Pharmacist’s Role

With the enormous increase in drug information access via DTC ads, online pharmacies are, needless to say, beginning to have a significant impact on the provision of pharmaceutical services [4]. Without regulation of the internet as a drug information provider, sources can vary widely in accuracy, completeness, and independence from promotion [4]. The pharmacist’s job, then, is to “[guide] patients in using the internet, telemedicine, and telepharmacy to full advantage” [4]. Right now, such an infrastructure is not totally in place: While the number of sources of medications is rapidly increasing, at the same time there is an “increased the distance between the consumer and the pharmacist” [4]. In addition, patients often switch providers, health systems, insurers, and pharmacies. In order to properly manage their drug therapy, pharmacists must work towards a single, comprehensive database on the drugs their patients take [4].

VI. The Quality of Online Pharmacies and the Drugs They Sell

As with general health information sites and science on the internet in general, drug information sites and online pharmacies are being scrutinized in terms of their quality and
accuracy. Richard Talley, in an editorial comment in the *American Journal of Health-Systems Pharmacy*, points out that “if medical quackery and unproven remedies were essentially harmless, their presence on the net would not be of concern. But experimentation with these remedies can be harmful—or at least preclude people from seeking effective, curative therapy. Unfortunately, the net facilitates deception and the promulgation of ‘cures’ that are anything but” [16]. Internet publishing offers national exposure of anyone’s views at relatively little expense, compared with broadcast and print media. Furthermore, the web does not have the gatekeepers who have traditionally kept the most dangerous and spurious reports out of print and broadcast [16]. Thus, quality has been a concern.

What people need to know is how safe and effective web-based drug information and products are (or are not). A study by Catherine Hatfield and colleagues looked at this question in 1999, and gave a more promising answer than was initially thought. Referencing the Top 200 Rx Drug List of 1996, Hatfield focused on the 30 prescription drugs dispensed in highest quantity to ambulatory care patients. These drugs were assumed to be representative of those medications for which consumers would be seeking information or sale on the internet [5]. Using Infoseek and AltaVista (the two most commonly used search engines at the time the study began) and various keywords, the researchers found a collection of internet drug information sites.

Websites found were evaluated for their overall quality. Criteria for evaluation of these sites included: inclusion of site sponsorship, identification of authors and contributors, listing of references, notation of recent updates, and ease of use [5]. (When assessing ease of use, the researchers noted whether the site’s drug database was readily accessible from the home page, whether there was inclusion of a help screen, whether the overall organization of the
site was good, whether there was a disclaimer against substituting the site’s information for the advice of a physician, and whether there were both brand and generic names used for the drugs [5].

Information found on these sites for each of the thirty drugs was compared against a template of correct information that was developed using the *Drug Information Handbook* and *Drug Facts and Comparisons* [5]. Presence or absence of the following information was noted:

1. pharmacology
2. drug interactions
3. precautions, warnings, contraindications
4. use in pregnancy
5. use during lactation
6. allergies
7. dealing with a missed dose
8. available dosage forms
9. storage
10. proper method of taking (time of day, with or without food, and frequency)
11. most common adverse effects (5 most common)

The study identifies four major internet sites as representative of the average websites that the average consumer would come across in a drug information search: MedicineNet.com, RxList.com, DrugInfoNet.com, and ThriveOnline.com. Both MedicineNet.com and RxList.com provided information on all of the 30 drugs studied, while DrugInfoNet.com and ThriveOnline.com provided only 62% and 72%, respectively [5]. All but MedicineNet.com provided 100% accurate information for the drugs they did include (MedicineNet.com was 98.5% accurate) [5]. However, MedicineNet.com included answers to more common questions such as what to do when a dose is missed, and what is the proper administration of the drug [5]. (It is interesting that the site with least accurate information, relatively speaking, is also the one providing more important answers to consumers.)
But overall, the sites ended up being somewhat more accurate than Hatfield and colleagues originally hypothesized—which is encouraging. In general, all four websites were similar in terms of the types and amounts of information they provided [5]. All four were up to date and had disclaimers. Using the indices and/or searching the database were relatively easy in all cases, and there was inclusion of both generic and brand names [5]. Three of the four listed either physicians, doctors of pharmacy, or medical boards as references; however, none included contact information for these references, for unknown reasons [5].

Another study by Gunther Eysenbach on the quality of online pharmacies selling Sildanefil (Viagra) returned less positive results. Eysenbach and colleagues searched the web for companies who offered either to issue prescriptions for Viagra online or to sell Viagra without any prescription at all. Researchers pretended to be a patient for whom the ordered drug (Viagra) was clearly contraindicated and who was trying to obtain an online prescription for this drug on the internet. Their test case was a 69-year-old woman giving a sexual history of having "no orgasm," with obesity, coronary artery disease, and hypertension, and taking several other prescription drugs [3].

The study identified twenty-two distinct companies, consisting of three different types: 2 required a written prescription by a "real" physician, 9 dispensed the drug without any prescription at all, and 11 issued an "online prescription" after an alleged physician reviewed the online order form containing medical questions [3]. Of this latter type, 10 were tested (8 being based in the USA). A total of 66 pills worth USD 1,802.84 were ordered. Three of the companies (including both European companies) delivered within 6, 10, and 34 days respectively, despite Viagra being clearly contraindicated (to being female and having heart disease/hypertension). In 80% of sites, no complete history was taken; in 70% inappropriate
medical terminology was used [3]. In only two cases was the order form reviewed by a physician who identified himself. Table 2.1 lists all of the sites tested as well as more specific data for each.

*Table 2.1.* Cyberpharmacies. (Reasons for non-delivery: F=not indicated in females, I=import restrictions, M=medical reasons, X=no reason given)

<table>
<thead>
<tr>
<th>URL</th>
<th>Origin</th>
<th>Remarks</th>
<th>Total Price</th>
<th>Delivered? Yes/No</th>
</tr>
</thead>
<tbody>
<tr>
<td><a href="http://kwikmed.com/">http://kwikmed.com/</a></td>
<td>USA</td>
<td>Did not ask for concomitant medications. Affiliate program.</td>
<td>US$ 216.00 (10x50mg)</td>
<td>No/F - &quot;cannot prescribe to females at this time&quot;</td>
</tr>
<tr>
<td><a href="http://www.viagraguys.com/">http://www.viagraguys.com/</a></td>
<td>USA</td>
<td>Offers to ship cimetidine (Tagamet) with sildenafil to enhance its effect.</td>
<td>US$ 130.00 (3x50mg)</td>
<td>No/F - &quot;even though there is no reason to believe that Viagra might be harmful to women ...in order to remain consistent with prescribing information...we are not filling prescriptions for women at this time.&quot;</td>
</tr>
<tr>
<td><a href="http://www.qualitymed.com/">http://www.qualitymed.com/</a> <a href="http://www.viagracafe.com/">http://www.viagracafe.com/</a></td>
<td>USA</td>
<td>Affiliate program.</td>
<td>US$ 196.00 (3x50mg)</td>
<td>No/F - &quot;we know of its benefits in both sexes, however, we are unable to fulfill any orders for females at this time&quot;</td>
</tr>
<tr>
<td><a href="http://www.viagra.nu/">http://www.viagra.nu/</a> Gibraltar (delivered from USA)</td>
<td>Gibraltar</td>
<td>Very short medical history questionnaire.</td>
<td>US$ 59.80 (2x100mg)</td>
<td>Yes - (34 days)</td>
</tr>
<tr>
<td><a href="http://www.mdbyphone.com/">http://www.mdbyphone.com/</a></td>
<td>USA</td>
<td>Charged credit card but did not deliver.</td>
<td>US$ 149.00 (5x100mg)</td>
<td>No/I - &quot;we are prohibited to deliver into Germany&quot;</td>
</tr>
<tr>
<td><a href="http://thepillbox.com/">http://thepillbox.com/</a> <a href="http://www.medicalcenter.net/">http://www.medicalcenter.net/</a></td>
<td>USA</td>
<td>Advertised as &quot;miracle drug.&quot;</td>
<td>US$ 236.00 (10x100mg)</td>
<td>No/I - &quot;due to your country's import restrictions, we are unable to ship into your country&quot;</td>
</tr>
<tr>
<td><a href="http://cyber.global-rx.com/">http://cyber.global-rx.com/</a></td>
<td>USA</td>
<td>Advertised as &quot;miracle drug.&quot;</td>
<td>US$ 228.00 (10x50 mg)</td>
<td>No/X - &quot;we must decline your order at this time.&quot;</td>
</tr>
<tr>
<td><a href="http://viagra.stiverson.com/">http://viagra.stiverson.com/</a></td>
<td>USA</td>
<td>Charged credit card but did not deliver.</td>
<td>US$ 194.00 (10x50mg)</td>
<td>No/M - &quot;the doctor was concerned about your heart conditions and the medication you are on.&quot;</td>
</tr>
<tr>
<td><a href="http://www.net-dr.com/">http://www.net-dr.com/</a></td>
<td>USA</td>
<td>German questionnaire, prescription by US doctor. Sent email warning to stop other drugs.</td>
<td>US$ 219.00 (10x100mg)</td>
<td>Yes (10 days)</td>
</tr>
<tr>
<td><a href="http://swisspharma.com/">http://swisspharma.com/</a> Switzerland (delivered from Spain)</td>
<td>Switzerland</td>
<td></td>
<td>US$ 99.70 (3x100mg)</td>
<td>Yes (6 days)</td>
</tr>
</tbody>
</table>

Overall, these results are not encouraging. The job of a pharmacist is to prevent contraindications, as well as to act as the checkpoint between the physician who prescribes
the medication and the patient who takes it to his ill health. Neglecting this responsibility appears to be a major problem with internet pharmacies. Another major problem is one which Eysenbach’s study does not have the scope to address, and that is the possibility that the drugs sent from these sites are counterfeit, adulterated, undated, or stored improperly—things which can significantly affect how effective or even harmful a drug can be.

VII. Taking Action

Currently, it is a violation of the FDA’s Food, Drug, and Cosmetic Act to sell a prescription drug without a valid prescription. Yet many sites continue to do so. The problem is that most of the regulation is under state jurisdiction. So, even if one state successfully shuts down an illegal website within its borders, the site theoretically still has forty-nine other potential locales in which to sell its prescription drugs [6]. But now that the federal government is starting to get involved, illegal websites can begin to get shut down for good.

In July 1999, the FDA announced that it was joining forces with state regulatory agencies and law enforcement groups to combat illegal domestic sales of prescription drugs. The agency signed agreements with the National Association of Boards of Pharmacy (NABP) and the Federation of State Medical Boards (FSMB). These organizations have made a commitment to help enforce federal and state laws against unlawful internet pharmacies [6].

Also in 1999, the Federal Trade Commission announced a program called "Operation Cure All," which aims to stop bogus internet claims for products and treatments touted as cures for various diseases. In the two years following, the FTC identified about 800 sites and numerous Usenet newsgroups containing questionable promotions. “These included sites that claimed to cure arthritis with a fatty acid derived from beef tallow, to treat cancer and
AIDS with a Peruvian plant derivative, and to treat cancer and high blood pressure with magnetic devices” [6].

The American Medical Association has also gotten involved, having adopted guidelines for doctors that specifically address internet prescriptions. These voluntary principles recommend that doctors who prescribe over the internet follow minimum standards of care. This includes examining a patient to determine the medical problem, discussing the risks and benefits of a drug with the patient, and following up to ensure the patient does not experience serious side effects [6].

The NABP mentioned above has identified some 200 US pharmacy sites on the internet. Drugstore chains on the web include CVS, Walgreens, Rite Aid, PharMor, and Drug Emporium [8]. At some chain sites, patients order their prescriptions online and pick them up at the local store. Most of the sites they have found do not accept new prescriptions, contrary to what Eysenbach’s study would lead one to believe [8]. In response to public concern of the safety of pharmacy practices on the internet, NABP developed the Verified Internet Pharmacy Practice Sites (VIPPS) program in the spring of 1999. The program consists of a coalition of state and federal regulatory associations, professional associations, and consumer advocacy groups providing their expertise in developing the criteria which VIPPS-certified pharmacies can then follow. Certification is voluntary. To gain the VIPPS seal of approval, internet pharmacies must meet legal and regulatory requirements (state licenses must be in good standing), agree to criteria concerning the patient’s right to privacy and the authenticity of the prescription drug ordered, adhere to a recognized quality assurance policy (after allowing NABP inspection of its site), and “provide meaningful consultation with pharmacists” [8]. Displaying the VIPPS hyperlink seal lets consumers know that the site is of
high quality. As of right now, there are only 14 online pharmacies in the VIPPS database; they are listed in Table 2.2.

Table 2.2. VIPPS Database Search Results

<table>
<thead>
<tr>
<th>Web Business Name</th>
<th>Website Address</th>
</tr>
</thead>
<tbody>
<tr>
<td>accuratepharmacy.com</td>
<td><a href="http://www.accuratepharmacy.com">www.accuratepharmacy.com</a></td>
</tr>
<tr>
<td>AdvanceRx.com</td>
<td><a href="http://www.AdvanceRx.com">www.AdvanceRx.com</a></td>
</tr>
<tr>
<td>Anthem Prescription</td>
<td><a href="http://www.anthemprescription.com">www.anthemprescription.com</a></td>
</tr>
<tr>
<td>Caremark Inc.</td>
<td><a href="http://www.caremark.com">www.caremark.com</a></td>
</tr>
<tr>
<td>Clickpharmacy.com</td>
<td><a href="http://www.clickpharmacy.com">www.clickpharmacy.com</a></td>
</tr>
<tr>
<td>CVS Washington, Inc., a.k.a. CVS.com</td>
<td><a href="http://www.cvs.com">www.cvs.com</a></td>
</tr>
<tr>
<td>DrugSource, Inc.</td>
<td><a href="http://www.drugsourceinc.com">www.drugsourceinc.com</a></td>
</tr>
<tr>
<td>drugstore.com</td>
<td><a href="http://www.drugstore.com">www.drugstore.com</a></td>
</tr>
<tr>
<td>Familyneds.com</td>
<td><a href="http://www.Familyneds.com">www.Familyneds.com</a></td>
</tr>
<tr>
<td>Medco Health Solutions, Inc.</td>
<td><a href="http://www.medcohealth.com">www.medcohealth.com</a></td>
</tr>
<tr>
<td>Omnicare, Inc a.k.a. Care for Life</td>
<td><a href="http://www.careforlife.com">www.careforlife.com</a></td>
</tr>
<tr>
<td>RxWEST Pharmacy</td>
<td><a href="http://www.rxwest.com">www.rxwest.com</a></td>
</tr>
<tr>
<td>Tel-Drug, Inc./CIGNA</td>
<td><a href="http://www.teldrug.com">www.teldrug.com</a></td>
</tr>
<tr>
<td>walgreens.com, Inc.</td>
<td><a href="http://www.walgreens.com">www.walgreens.com</a></td>
</tr>
</tbody>
</table>

Consumers can also look to the FDA for a list of tips on how to identify a reputable pharmacy on the internet, should they not see the VIPPS quality seal (see Figure 2.1).

Figure 2.1. FDA Consumer Tips for consumers who buy health products online.

- Check with the National Association of Boards of Pharmacy (www.nabp.net, (847) 698-6227) to determine whether a web site is a licensed pharmacy in good standing.
- Don't buy from sites that offer to prescribe a prescription drug for the first time without a physical exam, sell a prescription drug without a prescription, or sell drugs not approved by FDA.
- Don't do business with sites that have no access to a registered pharmacist to answer questions.
- Avoid sites that do not identify with whom you are dealing and do not provide a U.S. address and phone number to contact if there's a problem.
- Look for easy-to-find and understand privacy and security policies. Don't provide any personally identifiable information (social security number, credit card, and health history) unless you are confident that the site will protect them. Make sure the site does not share your information with others without your permission.
- Don't purchase from foreign web sites at this time because generally it will be illegal to import the drugs bought from these sites, the risks are greater, and there is very little the U.S. government can do if you get ripped off.
- Beware of sites that advertise a "new cure" for a serious disorder or a quick cure-all for a wide range of ailments.
- Be careful of sites that use impressive-sounding terminology to disguise a lack of good science or those that claim the government, the medical profession, or research scientists have conspired to suppress a product.
- Steer clear of sites that include undocumented case histories claiming "amazing" results.
- Talk to your health-care professional before using any medications for the first time.

It is important to note, however, that the NABP does not regulate online pharmacies—only state boards of pharmacy, with some oversight from FDA, have the authority to regulate online pharmacies [17].

VIII. An In-Depth Look at a Pharmacy that “Plays by the Rules”

Drugstore.com is one of the fourteen online pharmacies given the stamp of approval by VIPPS. The site has been operational since February 25, 1999 and is based in Redmond, Washington. Interestingly, it is headed by a former Microsoft executive. One cannot deny, then, that drugstore.com is not about making money; but at the same time, the site does strive to uphold quality drug transactions. Andy Stergachis, the Director of Pharmacy Services at drugstore.com, reiterates that the site prides itself on “playing by the rules” [8]. When purchasing drugs from drugstore.com, “the consumer needs to have a legitimate physician-patient relationship…We call the physician’s office or call the patient if there’s any question about the accuracy, validity, or completeness of the prescription order,” Stergachis says [8]. No order will proceed without first “collecting information from the patient on drug allergies, current medical conditions, and other medications”; this information becomes part of a profile kept for all drugstore.com customers [8].

Consumers who decide to do business with drugstore.com will be happy to know they can “order [their] prescriptions in three simple steps” [21]. Step 1: Shop the Pharmacy. Consumers must first find their desired medication in an alphabetical index; next, they will select their prescribed strength, quantity, and form, and add it to their cart [21]. Step 2: Create a Pharmacy Account. Consumers will now enter their email address and password; if they haven’t already done so, they will fill out a Health Profile, including all allergies, medical conditions, and other items of importance. Step 3: Prescription and Checkout.
Consumers can provide drugstore.com with their prescription in one of four ways: by mail, by a phone call from their physician, by a phone call from the site to their doctor, or by transfer from another pharmacy. Email notification is sent once the prescription has been received and approved. Payment can then be made either by credit card or by insurance or discount card. The site emphasizes full protection of privacy during the transaction. New prescriptions take about fourteen days to arrive, while refills take only about six to eight days. Another solid feature of the site is that consumers can opt to have emails sent reminding them to get a refill at a specified interval.

The disclaimer at the bottom of the home page includes the statement that the information found on the site is “not meant to substitute for the advice provided by your own physician” [21]. This, one supposes, is where drugstore.com is trying extra hard to play by the rules. Overall, the site is well organized and looks easy to use. It has all the attributes that would make it a clear candidate for the VIPPS seal it holds.

The high quality of drugstore.com is even more evident when it is compared to some of the lowest quality online “pharmacies” (there is a difference between prescribing sites and true pharmacy site, according to the NABP) [8]. Buy-Onlin-Prescription-Drugs.net advertises at the very top of the page in big bold letters that “no prescription is required” [19]. Right here should be a red flag for those concerned about getting safe and effective drugs that are healthy for them. Another real winner is Bestwebsitesheyourshop.com. I do not even need to describe the site for this one; the incomprehensible URL says it all [27].
IX. The Canadian “Problem”

While the FDA clearly has the authority to regulate US prescription drug and medical device advertising on the Net, the jurisdiction has its limitations. The internet is international, and US regulations do not apply to other countries [16]. One of the major foreign suppliers of prescription drugs to American consumers is Canada, a reality that carries with it several problems.

A 1999 study by the Governmental Accountability Office (GAO) found that “all Canadian samples [it tested] were comparable to approved [American] samples” [18]. Thus, while some argue that Canada online pharmacies are of equal (or greater) quality than domestic ones, others worry that since 1999 Canada has become more of a middleman, buying the drugs elsewhere and then selling them to Americans. The drugs that people think they are getting from Canada may actually be supplied by pharmacies in Europe, Australia, Israel, and Latin America [7]. The reason behind such a fear is that Canada may be spreading itself too thin. Many Canadian officials worry about their ability to maintain an adequate, reasonably priced supply of prescription drugs for their own population in the face of burgeoning American consumerism. Currently, Canadian drug prices are fixed and thus lower than American prescription drug prices—which is precisely why we are buying from Canada in the first place. Online versions of these Canadian pharmacies, despite more a socialistic health care system, are still capitalistic at heart; simply, they would rather sell a whole lot more of their drugs to a population ten times the size of that of their own country because they can make more money doing so—$800 million a year in cross-border sales, to be precise [7, 12]. But the supply of Canadian drugs does not meet the demand of American consumers. Therefore, Canadian pharmacies—feeling “stymied at home”—are branching out
and setting up operations outside of Canada “to buy drugs from around the world and ship them to US customers” [13].

The new arrangement is a far cry from the relatively simple practice of recent years in which Canadian internet pharmacies bought US drugs and shipped them to US customers. Americans did not worry because the drugs were coming from US-regulated factories and were vastly cheaper than the local drugstore. But globalization raises a question for American consumers who are tempted by discounts of 20 to 80 percent: Is it safe to buy these drugs from “God-knows-where?” [13].

CanadaRx.net is a company based in Hamilton, Ontario (a city just over the border) and has been operational since 1998. Although based in Canada, they run their operations from a free trade zone (where they do not have to follow prescription regulations) in Freeport, Bahamas. Christopher Rowland for The Boston Globe describes the scene:

At the back of the steel warehouse, pharmacists in lab coats are fetching bottles of prescription drugs from dimply lit shelves. They bear labels in French, Spanish, and Italian. Some come from New Zealand, 8,225 miles away. Next stop: Minnesota [13].

Exactly how many Canadian operations have set up shop elsewhere is unclear, but CanadaRx.net is most certainly not the only one. The Canadian International Pharmacy Association says it knows of operations similar to CanadaRx.net in St. Kitts and Barbados [13]. The FDA has repeatedly warned consumers of the risk of getting counterfeit, adulterated, or mishandled drugs from foreign manufacturers. However, no direct evidence has been uncovered linking smuggled prescription drugs to harmed patients [13]. In the meantime, hundreds of US consumers—the majority of them uninsured or underinsured—continue to rely on CanadaRx.net and similar sites to get their prescription drugs [13]. This is despite shipping methods that are clearly intended to evade US authorities.
The US government dealt its most crippling blow CanadaRx.net last summer when the US Customs Service seized 439 packages containing prescriptions in Miami. The seizure marked a new approach for the government, which has not tried to seize drugs from Canada. The FDA said some of the drugs were "suspicious in appearance" and may not have been authentic [13].

The North American Pharmatherapeutic Consultants Association (NA-PCA), a Vermont-based organization consisting of Canadian, Mexican, and American physicians and pharmacists. The group has developed an accreditation program to create quality standards that will “help North American consumers identify legitimate internet and mail-order pharmacies” [17]. But their main function of late has been to argue that the FDA uses scare tactics in an attempt to discourage Americans from buying prescription drugs anywhere other than domestically. The NA-PCA has stated that the FDA “has not provided clear evidence that drugs purchased from Canadian pharmacies have harmed patients…[but] has used the issue of uncertain quality as a scare tactic” [17]. They have gone on to say that the very reason prescription drugs are so expensive in the US is that “the pharmaceutical industry spends millions of dollars to lobby and support that war [on foreign imports]” [17].

The fact that people are buying drugs from Canada and Mexico is a reality that needs to be dealt with—and not via a witch hunt. Encouragingly, a bipartisan coalition of US senators is sponsoring a bill to authorize consumer importation from Canada, the European Union, Japan, and Australia with FDA oversight. Governors in Illinois, Wisconsin, Missouri, and Kansas have established an internet purchasing site for residents of their states that lists pharmacies in Ireland and Great Britain, not just Canada, where they can get discounts of 25 to 50 percent. The site was set up in defiance of the FDA, which hasn't shut it down [13].
In 2003, Canada’s National Association of Pharmacy Regulatory Authorities has contracted with NABP to use its program in their country—suggesting that change would be best suited to come from both sides [17]. In December of 2004, the Canadian government signaled that it wants to start cracking down on internet pharmacies that send cheap medicine to the United States without proper prescriptions. Other Canadians are not so eager to placate the US: Premier Gary Doer of Manitoba said that the plan to crack down amounts to “folding like a cheap suit” in the face of White House pressure and said it was “unrealistic to try to stem the tide in an internet age” [12]. Doer is most likely speaking for his Manitoba residents, who have benefited from the 2,500 jobs that online pharmacies created in this provinces (where most of the internet sites are based)[12].

It will no doubt take a while to get all of the rules straight when it comes to drug imports. In the mean time, Congress needs to consider the underlying economic issues driving consumers to risk their health by purchasing drugs from unfamiliar sources. It is sad that people have to sacrifice their health to get the best prices. The real problem here is that prescription drugs in the US are too expensive [18]. Canadian drugs are cheap because they fix their prices, plain and simple. But that does not necessarily mean this is the answer for the US. (As Morrison said, Americans and Canadians are—at least on a health care level—fundamentally different [29].) That also does not imply that we should allow unrestricted importation of Canadian drugs just because it is “too hard” or “too costly.” Are we really willing to jeopardize the integrity of our system and the quality of our drugs for economic gains [17]?
X. A Special Case?

Of the six million people reported to have bought prescription drugs online, how many of those have done so in contraindication to their best health? In most cases, only their doctors can say for certain. But in some cases, are doctors really more that much more informed than the patients themselves? Take Viagra for example: only the patient requesting Viagra can attest to the fact that he needs it; the doctor is most likely not going to follow him into his bedroom to see whether or not he is impotent. What the doctor can tell him, however, is whether or not he has heart disease or high blood pressure (which are contraindications for Viagra). But if a patient already knows that he does not have these problems, and also knows that he is impotent, does it really matter that he can buy Viagra online without a prescription?

Emergency Contraception is another drug in this category. Emergency Contraception (EC) is taken to prevent fertilization in women who have recently had unprotected sex at the right time of their cycle in which to get pregnant. EC is not a chemical abortion, contrary to what some may believe. It is actually a high dosage of a birth control medication that will prevent sperm from fertilizing an egg. Many people are morally opposed to EC as a form of birth control—but morality issues aside, is it really problematic for a woman to decide when she does or does not need to take EC?

Some legislators are debating whether or not to make EC available over the counter rather than with a prescription. Others are lobbying for certifying pharmacists to be able to prescribe EC directly [25]. Until either of these become reality, it is often difficult for women to obtain EC quickly—which is important given that there is a short window prior to fertilization in which the pill will be effective.
There are currently several websites willing to prescribe EC to be picked up immediately at a local pharmacy. Getthepill.com is one such site [23]. After taking a medical history to determine eligibility, the site’s online pharmacists phone in a prescription to your local pharmacy. The cost of an online assessment is $24.95 and does not include the price of the pills. (There is no fee if you are denied a prescription.) This website is available 24 hours, although prescriptions are not submitted to pharmacies between 10 pm and 8 am EST. Women must be US residents between the ages of 18 and 40 to be approved [24]. According to the website itself, it is “the most private prescription service available on the internet. Other sites may tell you that your medical information is protected … [but] may still release your contact or other non-medical information without your consent. At getthepill.com, all of your information is absolutely protected and will never be released to anyone ... ever!” [23]

Another option for women needing EC who would rather not get a prescription online is Not-2-Late.com, “The Emergency Contraception Website” [24], which also provides a link to Getthepill.com. Unlike Getthepill.com, Not-2-Late.com does not provide online prescriptions; rather, they provide a database of all EC providers that can be searched by area code. Users can type in their home area code to get a list of EC providers in their area, who they can then contact for a prescription. The only downside to such a site might be that it would take longer to actually get EC, especially on a weekend.

For women who fear they might be pregnant, time is of the essence. Personal standards (such as not wanting to get prescriptions from the internet) suddenly go out the window—but is that necessarily bad in this case? In terms of its impact on the physician patient relationship, the online availability of EC may not be as negative as other drugs. When a woman claims to be in need of emergency protection, there is not much more her physician
can do but to give it to her as quickly as possible. In this respect, online providers of EC are facilitating the physician’s job without his involvement at all. The specific case of EC is one which illustrates that the impact of the internet on the physician-patient relationship is not always negative, which is something to keep in mind for the subsequent chapters.
19. Buy-online-prescription-drugs.net [www.buy-online-prescription-drugs.net](http://www.buy-online-prescription-drugs.net)
21. drugstore.com [www.drugstore.com](http://www.drugstore.com)
22. Food and Drug Administration [www.fda.gov](http://www.fda.gov)
23. Getthepill.com [www.getthepill.com](http://www.getthepill.com)
25. Pharmacyaccess.org [www.pharmacyaccess.org](http://www.pharmacyaccess.org)
27. [various junk mail sent to my email, Nov. 2004 – Mar 2005]
CHAPTER 3

Making Health Care Electronic

The vision of a unified information network that delivers frequently updated, clinically relevant, highly valid, and deeply integrated medical information over the internet is technically feasible but will require widespread private and public collaboration.

~P. Robert Hubbs, *JAMA*, 1998

I. The “IT” Decade

In July 2004, Health and Human Services secretary Tommy Thompson heralded this decade as the “Decade of Health IT,” and subsequently outlined a ten-year plan for building the necessary infrastructure to improve health information technology (HIT) [17]. By some estimates, HIT could save Americans and the American health industry $130 billion per year after the infrastructure is in place. Compared to other sectors of the economy the health care industry has not kept up as far as learning to replace costly capital, labor, and materials with less expensive telecommunications technologies. Health care spends 3% of its total revenue on information technologies, compared with 9% for banking and finance [17]. To offer you a better idea of how much could be saved doing things electronically: A bank’s cost to process an in-person transaction is about $1.07, while a bank’s cost to process an internet transaction is only about $0.01 [21]. This example obviously applies to the banking industry, but the implications for health care are clear. According to David Angaran, exactly why health care has not made the switch is “complicated…, but the complex needs of health care information technology systems, the current economic climate, repeated mergers, and lack of sufficient capital have all played a part” [1]. In a more elaborated list form, these barriers include:

ii. lack of security

iii. higher priority of other projects
iv. immaturity of technologies
v. lack of a proven business benefit
vi. absence of sufficient numbers of qualified users
vii. lack of development tools
viii. high cost of implementation
ix. uncertainty about future business
x. lack of industry-wide standards
xi. not enough qualified developers [1]

What makes HIT development most difficult is the fact that there is no successful model for “electronicizing” health care [1]. Those interested in protecting a free-market approach to the internet have begun various voluntary efforts to develop nongovernmental standards. The Science Panel on Interactive Communication and Health has developed a standardized reporting template for developers and evaluators of interactive health communications media” [1]. The government, as we shall see, has made its own initiatives. In the end, however, collaboration will have to come from all sides, both public and private.

II. The Opportunity Gap

What is needed in terms eHealth differs depending on whom you ask. A study by the RAND Corporation estimated—possibly somewhat liberally—that Americans get the appropriate treatment for medical conditions only 55% of the time [17]. Thus, it would seem, there is a lot to be done, and a good amount of potential to get it done online.

Tommy Thompson listed the following as a few of the necessary improvements via eHealth: 1) making electronic medical records (EMR) for physicians’ offices and hospitals, 2) building an “interoperable health information infrastructure that connects clinicians,” 3) increasing consumer access to health information by closing the knowledge gap discussed in Chapter 1, 4) facilitating public health monitoring, quality of care measurement, and clinical research, and 5) making bar codes on drugs mandatory [17]. According to a 1998 article by
Robert Hubbs in *JAMA*, the most pressing needs are simplified online drug requests and prescribing, search and presentation standards for EMR, and appropriate hardware and software at all facilities where care is provided [16].

Another way to look at all of this is through an idea known as the “opportunity gap”—the discrepancy between what people want to get out of eHealth and what they are actually getting. Currently, the most frequent reasons for use of the internet include finding information about diseases, medications, and ways to alter a lifestyle (e.g., to quit smoking or to lose weight). But patients in a Rhode Island survey said they hoped to do the following things online in the near future: 1) Use the internet to make sure all the necessary tests and treatments are given; 2) Schedule an appointment with their doctor; 3) Compare their doctor to other doctors in terms of qualifications and incidence of malpractice; and 4) Place electronic medication refill requests. These are the things that patients want. But, it is important for everyone to remember that internet-based health administration is not just desirable to health care consumers, but to providers and payers as well—given the right infrastructure—in terms of the time and money that could be saved [21].

Ironically, what may widen the opportunity gap most is the consumer himself. As health care consumers become more and more empowered by physician-patient relationships that are increasingly in their favor, and as the average patient becomes more and more internet-savvy of the average consumer, expectations for speed, access, and convenience within the health care system grow. This is what Angaran refers to as the “internet-fueled empowerment of consumers” [1]. Closing the opportunity gap might result in improved access to care, greater efficiency in diagnosis and treatment, higher productivity, and better market positioning for the coming century [1]. But who is to say that consumer expectations will not
increase at the same rate? Moore’s law states that microchip computing power doubles every 18 months [1]; thus, we have not even begun to expect what we might be doing in the next ten years. Will we ever be satisfied with what we can do on the internet?

III. Physician-patient Email: The Next Big Thing

What has been suggested as the most feasible way to save time and money in HIT development is via physician-patient emailing—something which is already being done in some practices. According to a recent article by Milt Freudenheim in the New York Times (2005), doctors may no longer make house calls, but they are answering patient e-mail messages, and being reimbursed for it in many cases [11]. In a move to improve health care efficiency and control costs, health plans and medical groups around the country are beginning to pay doctors to reply to patients’ e-mail, just as they get paid for seeing patients in their office. While some computer-literate doctors “have been using e-mail to communicate informally with patients for years,” most have never been paid for that service [11].

According to Freudenheim’s article, Blue Shield of California pays doctors $25 for each online exchange, the same as it pays for an office visit. This program has been made available to 160,000 of Blue Shield’s 6 million health plan members. Blue Cross and Blue Shield plans in New York, Florida, Massachusetts, New Hampshire, Colorado and Tennessee are beginning to pay doctors similar amounts ($24 to $30, including any co-payment) for online consultations [11]. Some insurers pay a bit less for e-mailing, and patients in other health plans are charged a $5 or $10 co-payment that is billed to their credit card and relayed to the doctor [11]. Kaiser Permanente, the nation's largest nonprofit managed care company, has tested physician-patient messaging in the Pacific Northwest and is starting the program
this year in Hawaii and Colorado as part of Kaiser's $3 billion information technology program. Kaiser's salaried doctors get credits for messaging, adding to their pay [11]. On the Medicare front, a bill introduced in the House on February 11, 2005 was the first to include a provision to authorize Medicare to make "bonus payments" to doctors for email consultations [11].

Email seems to be especially useful for treating patients with chronic diseases or conditions, such as diabetes, who may have more regular questions than the average patient [18]. It is also helpful for patients who have trouble communicating verbally, or who are embarrassed to bring up sensitive issues during a check-up [18]. Email can also be used to gather pre-visit information such that exams are more productive and to the point [18]. Or, patients can ask follow-up questions and anything else they forgot to bring up when they were at the office [18]. Questions about correct dosage, for example, do not require a separate visit and are often more quickly and easily answered by email [11]. Both patient and physician can write and respond to each other’s emails at their own convenience without the stress and business of a doctor’s office. Patients, in this way, can gain more control over their care, time-wise. For doctors, the convenience of online exchanges can be considerable. They can offer advice about post-surgical care, diet, medication changes and other topics that can be handled “safely and promptly without an office visit or a frustrating round of telephone tag” [11]. By reducing the number of daily office visits, physicians should theoretically have more time to spend with patients who need to be seen in person [11].

Another advantage to email is that it provides automatic record-keeping, which can be useful in fending off medical malpractice lawsuits, since allegations based on undocumented telephone calls are often hard to rebut. "Good communications with patients is protective,"
said Frank A. Sloan, an economist at Duke University who has studied malpractice suits. "This kind of interaction is helpful" [11].

Online consulting is "one of the biggest changes to come to health care since the beginning of the electronic medical record itself," according to Judith R. Faulkner, chief executive of Epic Systems, a health information technology company based in Madison, WI [11]. Physicians and HIT specialists both say that email could be the catalyst helping to spur the changeover to electronic health care information systems [11]. Early research in clinics at the University of California, Davis, found that using email “improved the productivity of physicians, decreased overhead costs and improved access to doctors for patients, including those who still telephoned” [11].

However, there are some important issues to be considered before every physician in America jumps on the email bandwagon. Thomas Houston and colleagues conducted a survey in 2003 to gather the experiences of physicians who frequently use email with patients. A total of 204 physicians were interviewed who reported using email with their patients on a daily basis [15]. They averaged 49 years of age, were 82% male, and 35% primary care physicians (PCPs). The median time spent per email was 2 minutes. As was expected, physicians who were satisfied with their email use often cited the following as their top reasons for using it: “time saving” (33%) and “helps deliver better care” (28%) [15]. However, an unexpected 25% of those surveyed were dissatisfied with physician-patient emailing, despite their daily use of it. About 80% of that group cited “patient requesting” (80%) as their top reason for using email [15]. Dissatisfied physicians reported concerns about time demands, medicolegal risks, and “the ability of patients to use email appropriately” [15]. The fact that many patients request to use email—and at the same time
may not know how to use it appropriately—is an important factor to mention. For physicians who do not want to use email, it can introduce a real burden into their professional lives. It may be, however, something they will have to get used to if they want to stay in practice.

Other common concerns noted by Houston and colleagues were liability, unavailability of email to many patients, difficulties implementing new technology, and the need to train and satisfy office staff (especially elderly employees). The majority of subjects, however, would recommend the use of email to a colleague. The study concluded that an increase in email integration could “enhance time-saving aspects and improve patient education [leading] to more sustained use of this promising communication tool” [15]. In the end, “effective physician-patient communication is important to patient satisfaction, treatment adherence, and health outcomes” [15]. At the same time, quality of care cannot be sacrificed for increased efficiency or decreased cost. Both patients and physicians need to follow guidelines (the AMA has developed a list of guidelines for physicians) as to how to use email with each other appropriately. In some cases, a physical exam or a face to face conversation simply cannot be circumvented.

A 2003 survey by Madhavi Patt and colleagues of 45 “internet-savvy” physicians quotes these physicians as referring to their email use as a “double-edged sword” [18]. While using email can save them a lot of time in some cases, it can also add to their work load if the emails they receive are inappropriate in content (i.e., they really require a visit to the office) or in excessive numbers (i.e., many of the physicians worry about being inundated with questions). Some physicians also questioned what to do about their email should they go out of town [18]. Most physicians in the survey felt that in the absence of an established standard of patient use (i.e., a waiver, consent form, or set of guidelines) that dictates expectations
about response time and appropriate content, they have to subjectively pick and choose which patients they allow to contact them by email. In other words, they have to “pick the ones [they] know won’t abuse it” [18].

While some physicians are struggling to deal most appropriately with patient requests for email communication, others are more burdened by unsolicited emails. According to a 2000 review by Gunther Eysenbach,

Every physician who has published his email address or who runs a medical website receives unsolicited emails from patients he or she has never seen before. Patients use email to ask medical questions to physicians unknown to them, or sometimes even describe their symptoms and expect a remote diagnosis. Health portal sites and specialized services responded to this consumer demand for "virtual interaction" with physicians, and have set up "ask-the-expert" services and "cyberdoctor" services, which offer such advice for free or for a charge [8].

Here, the problem is no longer how to use email appropriately and with whom, but rather what is to become of the physician-patient relationship when email is the sole link between the two? Eysenbach’s paper seeks to discover how best to deal with unsolicited emails such that a traditional physician-patient relationship is still intact. He defines physician relationships in two categories: 1) Type B (the bona fide relationship), referring to traditional clinical encounters or telemedicine applications where there is either a pre-existing patient-physician relationship or, at the very least, access to the patient’s electronic health record; and 2) Type A (absence of pre-existing physician-patient relationship), referring to online interactions that lack many of the characteristics of bona fide interactions, most notably the pre-existing relationship [8]. In a Type A interaction, the relationship between patient and physician is less well-defined and more prone to misunderstandings than in traditional Type B physician-patient encounters. In addition, the situation is difficult for the physician in that he or she may not be sure about the ethical duties and the legal consequences of his or her
actions. Guidelines for unsolicited emails may help to better define such contacts to avoid misunderstandings. But, there are justified concerns that what Eysenbach calls Type A encounters may "disturb delicate balances in the patient-physician relationship, widen social disparities in health outcomes, and create barriers to access" [8]. In short, electronic communication is neither inherently unethical nor readily acceptable for medical practice. Rather, the emergence of electronic communication calls for a "reexamination of the necessary values for good communication in the patient-physician relationship" [8].

In a separate study, Eysenbach & Diepgen provided a thorough analysis of 209 unsolicited emails sent to a university department of dermatology in a four-month period in 1997. Forty percent of all emails could have been answered by a librarian; 28% of all emails were suitable to be answered by a physician via email alone; and in 27% of the cases a medically-sound answer was not possible without seeing the patient. In 34% of the cases, patients only wanted general information about a condition; but in another 11%, the person gave a list of symptoms and wanted to hear a diagnosis [8].

In response to the latter 11%, Eysenbach and Diepgen conducted a subsequent study to discover how real physicians are responding to such impossible requests. The researchers sent an unsolicited email from a fictitious patient describing an acute dermatological problem to 58 physicians and webmasters in order to explore the response rate and the types of responses [8]. Fifty percent responded to the fictitious patient request; of those who responded, 31% refused to give advice without having seen the lesion, 59% explicitly mentioned the correct "diagnosis" in their reply, and 17% gave detailed treatment advice [8]. Ninety-three percent recommended that the patient see a physician. Overall, two main arguments were brought forward by the replies: 1) the impossibility of making a diagnosis
via email without an examination ("The diagnosis is unclear because we cannot look at your exanthema."), and/or 2) the lack of resources to reply to all such enquiries. Some of these responses were suspected to be standard replies [8].

A similar email was also sent to commercial “cyberdoctors” who explicitly offered medical advice on the internet. Ten free and seven charging cyberdoctors were contacted. A total of ten cyberdoctors responded; three declined to give advice because dermatology was not their area of expertise; seven cyberdoctors provided advice (two for free, five for a charge). The advice given by five cyberdoctors was accurate, and the "correct" diagnosis (herpes zoster) was mentioned. In the remaining two cases the advice was highly questionable: one cyberdoctor recommended a homeopathic medicine, the other unusual methods such as drinking rain water and eating red clover and dandelion [8].

What the results of these two studies emphasize is the need for better definitions of concepts like “diagnosis” and “treatment” so that their limitations are completely understood in a Web-based context—and so that both physicians and patients are on the same page when unsolicited emails are concerned. Patients are not always able to distinguish between questions that are suitable to be answered via email and those that are not [8]. There seems to be consensus that physicians can indeed establish a physician-patient relationship online, but such a relationship depends on whether or not their reply can be considered to be an act of medical practice, rather than just an act of "information brokerage” [8]. However, there will always be a grey area, and it is the “responsibility of the physician to act according to where on the continuum the patient's problem is located, and according to which ‘media’ of interaction are available” [8]. Moreover, it is essential to clearly state the nature of the interaction to the patient [8].
The American Medical Association (AMA) has drawn up recommendations for "Physician Advisory or Referral Services by Telecommunications" [24]. These acknowledge that teleadvice services can be useful for the public and are relatively clear as to what can be considered reasonable and ethical [8]. Other professional codes or ethical guidelines, in contrast explicitly discourage or even forbid giving any concrete medical advice via telecommunication computer networks in the absence of a pre-existing physician-patient relationship. Against this background Eysenbach has argued for a reconsideration of such restrictive guidelines for the sake of preventing otherwise unqualified “cyberquacks” from taking over the eHealth industry [8]. In other words, it is better for everyone if real, competent doctors are answering these unsolicited questions, given that there is full observance of disclosure, confidentiality, and quality control.

There are two main problems with eHealth in the larger context of the health care crisis: 1) Physicians are being bombarded with more and more online health information which they must be able to sift through while still providing the same quality of care; and 2) HMO’s are asking physicians to practice medicine at an increasingly fast pace [16]. As a result, physicians are themselves spread thin despite the fact that technology should be making their lives easier. Email is just one of many factors. Until physicians have been given convincing evidence that the internet can help them provide better care, they are not likely to adopt the practice in large numbers [9]. Only 13% of physicians in a study by June Forkner-Dunn stated a willingness to send email to patients; this finding is in contrast to the studies mentioned above which may have given the impression that email use is common among doctors (since they focused only on the ones that do). On the flip side, upwards of 90% of patients in that same study wished to communicate with their physicians via email [9]. (Only
9% of patients have actually done so, according to the Pew Internet and American Life Project [10]. This demand has clearly been accelerated in a technically-minded, electronically-equipped age [18]. Until physician-patient email usage is more widely developed, a significant opportunity gap will continue to exist in terms of how patients want to communicate with their providers.

IV. Electronic Prescribing

A topic akin to physician-patient email is electronic prescribing, an application of technology which many physicians still do not subscribe to for many of the same reasons they do not use email. Patt’s survey found that “there were comments, primarily from physicians who do not currently prescribe medications online, concerning the appropriateness of [electronic prescribing]” [18]. As Vice President of the Federation of State Medical Boards (FSMB) George C. Barrett explains, “prescribing over the internet is telemedicine, but it is not telemedicine as originally envisioned” [22]. Telemedicine, he says, assumes that the initiating physician conducts an appropriate medical exam before prescribing any drugs [22]. It is currently illegal for physicians or pharmacists to dispense prescription medications in the absence of a legitimate physician-patient relationship [22]. There is very little latitude on what constitutes that physician-patient relationship, according to John M. O’Bannon III, a member of the AMA Council for Ethical and Judicial Affairs. O’Bannon does not preclude the possibility that physician-patient relationships can be established over the internet, nor does he object to internet use once that relationship is established, but, he says, “that day is not today” [22]. Right now, with the issues discussed in Chapter Two near the forefront of medical and political debate, it is important for qualified physicians and administrators to get prescribing done right. Similarly, as was discussed with
physician-patient emails, if the right people are not answering the questions and prescribing the drugs, “cyberquacks” may step in.

A 2004 report from the eHealth Initiative (an independent, non-profit affiliated organizations whose mission is to “drive improvement in the quality, safety, and efficiency of healthcare through information and information technology” [7]) highlights where we stand with electronic prescribing thus far, as well as some of the future implications. Despite the possible benefits of electronic prescribing, adoption is still modest. Current surveys estimate that between 5% and 18% of physicians and other clinicians are using electronic prescribing. Key barriers to clinician adoption include “startup cost, lack of specific reimbursement, and fear of reduced efficiency in the practice” [7]. Therefore, certain incentives need to be offered to physicians in order to spur adoption and use of electronic. Patient confidentiality must also be ensured. In addition, drug vocabularies and prescription forms need to be standardized and integrated into electronic health records [7].

Given the proper infrastructure and incentives, the advantages of electronic communication are undeniable: “it is faster, more work-efficient, more secure, more reliable, less error-prone, and less prone to abuse than paper or fax prescriptions” [7]. The errors and adverse drug events seen in ambulatory care centers can be common, serious, and preventable, according to research, if electronic methods are used instead [7]. Economically-speaking, the national savings from universal use of electronic prescription methods could be as high as $27 billion [7].

V. Electronic Medical Records

Something which has come up several times in this discussion and which has also initiated a good deal of debate is the idea of electronic medical/health records (EMR or
EHR). Like physician-patient email and electronic prescribing, EMR is another seemingly great idea which has failed to catch on as yet.

An internet-based electronic medical record for pregnant women, eNATAL, is one small example of EMR that offers an interesting case study as to why making health records electronic is slow to become common practice. Following its launch in 2002, Dr. Don Miller predicted that his brainchild would snowball into something that every obstetrician-gynecologist in the land would sign up for. “Long story short, it didn’t” [5]. This failure was despite the fact that eNATAL would only cost about $20 per patient, which is relatively cheap by health care standards [5]. As Miller himself explains, “everyone thinks technology is a great idea, but few people actually want to use it” [5].

Other analysts have suggested that since doctors are not the ones who benefit most directly, they are slow to change their ways—but a simple calculation stands in the face of that claim: If Obstetricians, on average, deliver 144 babies a year, and an EMR such as eNATAL eliminates the need for approximately $300 worth of lab work ordered for the 37% of patients whose paper record is not immediately available, that saves more than $13,000 a year per obstetrician (after the cost of implementation) [5]. And this is just for OB-GYN.

It does not seem, however, that doctors are thinking of EMR that way. In fact, the adoption of HIT in the health care industry in general is so slow that “even die-hard capitalists are looking to the federal government to pressure the foot-dragging industry” [5]. Doctors certainly would stand to benefit, but since payers in the health care industry (i.e., insurers, employers, and the government) are the primary beneficiaries of HIT, it seems that the burden of financing the implementation will rest mostly on their shoulders [5].
A novel approach to EMR has come from Dr. Carl Franzblau, associate dean of graduate medical sciences and chairman of the biochemistry department at Boston University. Franzblau recently introduced Med-InfoChip, a simple USB device that stores personal medical information while also doubling as a fob for one’s keys. Selling for $69.95 for a single-user version, the device offers an attractive alternative to those who fear the seemingly imminent idea of embedding a computer chip under the skin. Plugging the device into any USB port allows access to its contents without software installation. Medical information is loaded by the consumer, and may also include personal identification information, emergency contacts, as well as a photo. Even EKG’s, birth certificates, and X-rays can be scanned in, as can doctors’ and nurses’ notes.

Franzblau chose not to password protect these devices for fear that they could not be accessed in an emergency. He is, however, working on a dual password scheme—one password to view the contents only, and another to change them. He explains that “the beauty of the chip is that everything is in your possession…It’s not on the internet or some place where people might be able to crash through it” [25].

Another question that has been raised to Franzblau is how to standardize the information loaded on each device. Some argue that the information is only as good as what the patient enters himself. Franzblau would counter that “some information is a hell of a lot better than nothing” [25]. He is also working on a medical electronic information system built around the InfoChip which would allow instantaneous downloading of contents by emergency staff.

Despite some kinks that need to be worked out, Franzblau’s device is a step in the right direction: towards harnessing the power of technology. In the future, this device and similar ones may become “important tools for interaction between patients and doctors” [25].
VI. HIT Overhaul from an Administrative Standpoint

If it is not yet apparent, fundamental change is needed in our outmoded, internet-averse system of health care. The United States health care system must embrace the e-revolution by exploring and taking advantage of the potential benefits of HIT in improving quality of care [9]. Thus, the internet promises to have a central role in retooling a trillion-dollar industry [9]. With incentives like this, it is to be expected that some of the biggest players in the health care industry—namely the government and big business—will get involved in the implementation of HIT.

In an Executive Order issued on April 27, 2004, President George W. Bush called for widespread deployment of HIT within 10 years. As part of this announcement, he formed the Office of the National Coordinator for Health Information Technology (ONCHIT). An important aspect of the President's initiative is the development of a “nationwide interoperable health information technology infrastructure that can facilitate improvements in safety, quality, efficiency, and care coordination” [6]—which sounds great, but exactly how does the government plan to do this? Technically, the government is not planning to do anything; the government “won’t push mandates for health information technology…Instead [they] will push standards and demonstration projects as the quickest way to wire the healthcare system” [20].

A 2004 meeting of the National Health Information Infrastructure (NHII) council yielded a list of recommendations for HIT implementation. Among them were the following:

- Development of a stable source of federal funds, coordinated with state funds
- Institution of federal “safe harbor” against fraud and abuse, along with anti-kickback statutes and regulations
iii. Federal and state support for education and training programs relating to health informatics—both public health-wise and in health professions

iv. Leadership of the federal government in HIT implementation

v. Increased payment incentives to encourage investment in IT


Simply put, the government “won’t regulate EHRs into existence or use brute force” [3].

While the government is providing incentives and muscle, the private sector will have the job of ultimately making functional HIT a widespread reality [3]. It certainly will not be easy and for several reasons. First, much of the expensive technology is still clumsy and hard to implement. Worse, even effective products can be made obsolete by new technology. Doctors, in turn, want products that are guaranteed to improve their practice, and worry that investments in EMR are too risky [3]. Ultimately, the problem is that no one has the incentive to be the first one to invest in HIT. An analogy might help:

If you are the first one to put in a fax machine, what are you going to do with it? If you’re the last one, you’re immediately connected to everyone else. Thus, where there are only a few users, using interoperable EHR can be a bad value. Once nearly everyone is using EHR, getting on board is very cost-effective. Health providers, particularly small physician offices, have a strong incentive to wait [3].

Yet another problem with HIT implementation is that our current electronic infrastructure still is not where we need it to be. We cannot go forward with complicated HIT ideas until we have the basics down first. For instance, the CDC estimated in 2001 that only 68.1% of US counties have high-speed internet access and can receive a broadband message [12]. The CDC recommends that first and foremost there needs to be “creation of a data network that would link health care professionals with public agencies at all levels of government, so that alerts could be quickly disseminated and information shared when threats to public health are detected” [12]. This recommendation is, of course, coming from a disease-control standpoint,
but the message is clear: certain areas of HIT may not be the most feasible yet. Without bringing satisfactory broadband service to all regions of the US, HIT will quickly become—as some parts of eHealth already are—“a tool of the haves”[3].
CH. 3 REFERENCES


10. Fox, Susannah, and Lee Rainie. The online health care revolution: how the web helps Americans take better care of themselves. Pew Internet and American Life Project, 26 Nov 2003, [www.pewinternet.org](http://www.pewinternet.org)


CHAPTER 4

Web-brokered Transplantation

In the end, the better ideas carry the day.

~Sir James Frazer, British anthropologist

In what may seem like a divergence from the previous chapters, this essay will now look
at the incidence of web-brokered organ transplantation as a focus study within the larger
context of eHealth information. The huge deficit of organs in this country is yet another
pressing problem in health care, although it perhaps is not given enough attention by policy
makers. A recent survey by the Coalition on Donation found that while 9 out of 10
Americans support organ and tissue donation, only 3 out of 10 know the proper steps to take
[2]. Meanwhile, because of stringent requirements for donation, it has been estimated that
only about 1% of all deaths in the United States occur under circumstances that would allow
for transplantation [1]. In other words, 1% of all annual deaths could be prevented if organs
were not in such short supply. Thus, there is yet another gap in the health care system, one
between organ donors who want to give and recipients who need to receive, both of whom
exist in a construct that has failed to bring them together.

We need more organs, plain and simple, but before we can get them some major ethical
questions need to be sorted out—mainly, is an organ considered one’s property, and as such
can it be sold? In the absence of adequate policy for getting organs quickly, patients are
(again) taking matters into their own hands by (again) turning to the internet for a solution. In
the end, we arrive back at the same issue of patient autonomy and the question of what
people should have control over as they struggle to live a long and healthy life.
I. Background on Organ Transplantation

i. Short-comings of UNOS

As of December 14, 2004 at 11:07 pm, there were 87,130 candidates on the United Network for Organ Sharing (UNOS) waiting list [15]. By some estimates, another name is added to the waiting list every thirteen minutes [2]. Of those currently on the list, “less than half…are expected to live long enough to receive the needed organs because expected waiting times are now beginning to stretch into years. At least sixteen lives are lost each day (more than 6000 a year) as a direct consequence of this shortage [1].

The UNOS is a non-profit organization that operates the Organ Procurement and Transplantation Network (OPTN) under a contract from the federal government, the goal of which is to “continuously evaluate new advances and research, and use this new information to improve organ transplant policies to best serve patients waiting for transplantation” [15]. But it would seem, from the staggering number of people who die waiting for organs, that UNOS is not doing enough at this point to “best serve” patients. As to what should be done about this is open to debate.

ii. Organ Procurement

What are the current methods of organ procurement? The OPTN presides over 55 organ procurement organization (OPOs) in the US—58 if Puerto Rico is included. These are non-profit groups that are concerned with cadaveric organ procurement only. They are assigned a particular geographical area and operate on federal money and private donations. Their job is to acquire organs from recently deceased people and then enter these organs into the allocation system administered by UNOS. UNOS will then direct the organs to patients according to their rank on the national list, but will also consider the location of the organ when assigning it to a compatible recipient [1].
considered within the local area first, then regional area, and lastly the national level—presumably to minimize the distance that the organ has to travel [15].

The specifics of how organs are procured is severely limiting on their supply. The steps of organ procurement begin with the identification of suitable cadaveric donors. Such donors must die within a hospital and must have healthy, well-functioning organs that are free of infection and cancer at the time of their death. Then there is the question of consent. Under the Uniform Anatomical Gift Act of 1967, family permission is not required if an organ donor card or other valid document of intention has been signed (checking the back of your license does not count). In practice, however, permission of surviving family members is generally sought even in cases where a valid donor card is present. In “clear violation of the 1967 act, the organs frequently are not collected if the family denies consent” because OPTN does not want to confront families who have just lost a loved one [1]. (They have no incentive to, being a non-profit organization.) What makes families deny consent could stem from any number of reasons, but some researchers have speculated that the party making the request for the organ donation—i.e., the physician, nurse, or organ procurement officer—could be one of the major determinants influencing the family’s decision [1].

With all of these limitations in place, it is hardly surprising that shortages have persisted year after year, despite ongoing efforts to increase supply through expanded public and professional educational campaigns [1]. In fact, various estimates suggest that only about one-quarter to one-half of all potential donor deaths result in organ donations. Thus, a more effective procurement system “could potentially double or even quadruple the number of cadaveric organs collected” [1].
iii. A Futile Attempt?

Recently, the course of action has been to increase spending on educational measures—public advertisements and professional training programs—that will increase the general awareness of the great need for organs. An economically-minded study by T. Randolph Beard and colleagues seeks to explain why this increased spending on education is unlikely to work. First, the educational campaigns are spread too thinly over the whole population, most of whom are unlikely to ever have to make the decision about donating their or a family member’s organ. Second is the law of diminishing returns, which implies that benefits from increased spending should already be visible since it has been more than a decade since such spending programs began. The reality is that things are not getting better: while kidney donations from deceased donors in the US increased by only 33% from 1990-2003, the number of people waiting grew by 236% [5]. Third, research indicates that “an increase in educational expenditures of approximately $21,300 for professional education and $55,500 for public education would be required to generate one additional cadaveric donor. These expenditure levels are well above current estimates of likely market-clearing prices for cadaveric organ donors [which place] cadaveric organ donor prices within the range of $500-$1500 per donor” [1].

iv. Marginal Gains

Policy makers are being forced to look elsewhere for a resolution to the organ shortage. In recent years, they have tried to increase the organ supply with those of marginal quality from “less traditional” donors. In the past, an age limit on donors was generally applied, but that limit was increased from 50 to 55 during the mid-1990s; more recently, an explicit age limit has been dropped, and a more subjective case-by-case evaluation is now used [1]. Patients on the wait list may opt to receive from these “less traditional” donors if they choose
to risk lesser quality organs in return for shorter wait times [15]. For kidney donors, for example, the group of less traditional donors breaks down into two categories: 1) those who are 60 years of age or older, and 2) those who are age 50 to 59 but who have hypertension, creatinine levels greater than 1.5 (an indication of kidney function), or who died of a cerebrovascular accident (for cadaveric donors) [15]. But even with the addition of these lesser quality organs to the supply, the wait list still remains close to 90,000, not to mention that patients who receive these organs are often back on the list a few years later because their organ did not last long.

v. Financial Compensation for Donors

Another option which has been brought up over and over again—only to be rejected just as many times—is financial compensation for donors (both cadaveric and living). According to the 1984 National Organ Transplant Act (NOTA), US law prohibits “any payment to organ donors or their surviving family members to encourage increased collection rates” [1]. Those in the medical and transplant community have typically been the ones to resist lifting the ban on payment, citing ethical concerns. These ethical concerns center mainly on the potential for abuse of the system by living donors should payment be allowed. The existence of organizations such as Organ Watch is evidence that such abuse is already occurring. Organ Watch is an independent self-supporting documentation center launched at UC Berkeley in 1999 to investigate illegal organ trafficking. The need for this project grows first, out of the work of the Bellagio Task Force on Securing Bodily Integrity for the Socially Disadvantaged in Transplant Surgery (1994-1996), which had reported (among other things) the sale of organs in Third World countries. Berkeley Anthropology Professor Nancy Scheper-Hughes and colleagues conducted ethnographic research in sites in Brazil, India, and South Africa during 1997-1998. Their findings reveal that “a small but growing number of
the world’s poor are offering up their body parts for sale, and kidneys are the most commonly purchased organs” [5]. Organ sellers were most often from the following countries: Peru, Bolivia, Brazil, Turkey, Moldava, Romania, Egypt, Israel, Iran, India, China, and the Philippines [5]. Buyers, in contrast, were most likely to be from Canada, the United States, Italy, Israel, Saudi Arabia, Oman, Hong Kong, Australia, and Japan [5]. The fees received by kidney sellers, as an example, are shown in Table 4.1.

<table>
<thead>
<tr>
<th>Country</th>
<th>Asking Price (USD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Iraq (pre-war)</td>
<td>$750-$1,000</td>
</tr>
<tr>
<td>Philippines</td>
<td>$1,500</td>
</tr>
<tr>
<td>India</td>
<td>$1,500</td>
</tr>
<tr>
<td>Moldava and Romania</td>
<td>$2,700</td>
</tr>
<tr>
<td>Brazil</td>
<td>$6,000</td>
</tr>
<tr>
<td>Turkey</td>
<td>$7,500</td>
</tr>
<tr>
<td>Peru</td>
<td>$10,000</td>
</tr>
<tr>
<td>Israel</td>
<td>$10,000-$20,000</td>
</tr>
<tr>
<td>United States</td>
<td>$30,000</td>
</tr>
</tbody>
</table>

Clearly, the potential for prices to get out of control is a real one. Yet, economists such as Beard argue that once the market for organs reaches equilibrium, prices will be in the range of $500-$1500 per donor [1]. It is impossible to tell what would really happen until the ban is actually lifted. In the meantime, Beard places the blame for patient deaths on policy-makers:

Those opposing a market approach bear the heavy burden of suggesting a feasible non-market alternative, or else explaining how the current rate of patient deaths is an acceptable price to pay in defense of a questionable moral claim [1].

Other proponents of compensation have taken a more philosophical approach to support of organ-selling as something that should not be morally loathsome. Matthews argues that organ-selling is “in accordance with Judeo-Christian values” where “the proper attitude with respect to organs and other bodily tissue is that while it would be considered a great
humanitarian act for a person to donate an organ, there should be no ethical stigma attached to someone who desires compensation” [3]. He goes on to make the following analogy:

It would be kind of educators to donate their time to our children and beneficent for grocers to give away their food. Yet no one accuses teachers or grocers of undermining morals by accepting payment for their work or goods. The fact that people usually receive compensation for their goods and services does not preclude them from being generous on occasion. When a major tragedy occurs, vendors often donate products—food, clothing, tools, etc.—and people often volunteer their time to help the victims. But these acts of generosity are the exceptions, not the rule—and it is precisely because they are exceptional that we find them praiseworthy [3].

While Organ Watch and similar groups illuminate the detrimental effects of organ trafficking on Third World countries, Matthews argues that they actually could be benefiting: “Were the poor individual [in a Third World country] permitted to sell a kidney, he or she could use the money thus earned to start a business and perhaps emerge from poverty. It is not at all clear that, in the Third World, a poor person with two kidneys is better off than a middle-class person with one”[3]. Should it not be a person’s right to sell whatever part of his body he wants? If so, prostitution should probably be legal as well. Jacobs argues that “poor people are more likely to be coal miners or go fight in Iraq or do many kinds of things for money that are more dangerous than being a kidney donor” [13]. But does that make it right?

II. The Internet in the Context of the Organ Shortage

i. *What’s Happening in Denver*

On October 20, 2004, Robert Hickey got the new kidney that he needed. But, it was not from a family member or friend; it was from a donor he had met on MatchingDonors.com, a for-profit organ brokerage web site. Since then, there has been an explosion of debate as to whether this procedure was ethical or not.
The procedure was performed at University of Colorado Medical Center in Denver. Dr. Igal Kamead was a member of the transplant team, who, after discovering how Hickey and his donor had met, deliberated for two days about the ethical implications of what they were about to do before deciding to proceed [10]. Since then, Kamead and hospital administrators have refused to perform any more of these web-brokered transplants, saying that the first operation had only been a “compassionate exception” to their rule [10].

Donald Huttner was turned down just weeks after Hickey’s transplant. He had also found a possible donor on MatchingDonors.com. Karen Traxler was another to be denied. She thought her doctors would be as thrilled as she was when she tracked down seventeen people over the internet that might be able to donate the kidney she needs. Instead, she was met by physicians who accused her of trying to stir up trouble [10].

ii. Various Arguments

The American Society of Transplant Surgeons recently issued a statement opposing efforts to line up a donor for a specific recipient [10]. They cite the potential for abuse when patients and donors negotiate directly, rather than going through established, third-party organizations [10]. Doctors like Kamead worry that the national waiting list for transplant organs will be undercut and that the patients themselves will be vulnerable to exploitation [13]. In an interview, Kamead explained, “if we open it up and allow people to negotiate—donors and recipients over the internet—we always create the risk that money will be exchanged between the donor and the recipient.” This is the same issue investigated by Organ Watch, only the internet makes brokerage and exploitation that much easier. Some have jokingly called online brokerage a “dating service for kidneys” [13]. “If anybody really
wants to donate a kidney,” Kamead goes on to say, “he can go to a kidney transplant program, knock on the door, and say ‘I’m here to donate one of my kidneys’” [10].

Few dispute the potential of the internet to add power and reach to efforts to match patients with kidneys, livers, or lungs, the organs for which transplants are most commonly available. But there is no consensus yet among doctors and specialists about how that might be done [13]. Many doctors question why, if the internet is such a good match-maker, more of the 87,000 candidates on the waiting list are not going online to get their organs. There is doubt that many of the website hits will result in a medical match. In addition, critics have objected that public solicitation of organs is easier for those who are computer savvy or who have money to invest in web-brokerage sites that charge a fee [13].

However, a few doctors are left wondering if they are not violating the Hippocratic Oath they took in medical school—to give all patients the best care possible—by refusing to perform web-brokered transplants. For every doctor who fears that money is on the mind of would-be donors, there is one who believes that payment might be the only way to increase the organ supply [13]. Perhaps having more public solicitations can, in and of itself, help to increase the overall number of donors [13].

iii. A Closer Look at Web-brokerage Sites

1. MatchingDonors.com

MatchingDonors.com, the Web site implicated in the Hickey transplant, describes itself as “a venue where patients and potential donors can meet and communicate, and hopefully expedite a donor agreeing to give a patient a much needed organ” [14]. Advertised in bold letters at the top of its home page is the statement that “it is absolutely against the law to have any kind of financial benefit from organ donation” [14]. Right under that it warns that “there
is a potential for complications for this type of surgery” [14]. If nothing else they are being up front about what a donor might be getting into.

The site is also up front about its fees. While use of the web site is free-of-charge for donors, patients must pay monthly to post their particular case. A seven-day trial costs $19; one month is $295; three months: $441; six months: $582. The site claims to waive all fees for those who cannot afford them. How this is determined was not specified up front. While the site is not promoting the sale of organs by any means, they seem to be taking advantage of desperate patients on the bottom of the UNOS waiting list. For instance, the site claims that “the clinical ethics committee at Presbyterian/St. Luke’s Medical Center in Denver decided last week that there was nothing wrong with a match made on MatchingDonors.com” (as of Dec. 14, 2004) [14]. This statement is a blatant contradiction to the new policy of the American Society of Transplant Surgeons, and as such would seem to say to patients “it’s ok to invest in our site, you can get the transplant at this particular hospital even though you may have heard otherwise.”

Monthly fees aside, there did appear to be some helpful discussion of living donorship—and since the site displays the Health on the Net logo, we may be relatively certain that the content of the site is medically-sound. Information included reasons to become a donor, facts about donor compatibility, and federal cost-coverage of medical expenses for donors [14].

2. LivingDonorsOnline.com
In contrast to MatchingDonors.com, LivingDonorsOnline.com is a non-profit web site for the purpose of advocating living donors through education and support. Michael Murphy, administrator of livingsdonorsonline.com, donated a kidney to his sister more than a decade ago, and says he knows of three transplants that have occurred between patients and donors
who met on the site, “surgeries that apparently stirred less concern than the University of Colorado’s because of the site’s non-profit status” [13].

Like MatchingDonors.com, the site contains various information for would-be donors, including the history of living organ donations, recipient survival rates, and questions to ask oneself before becoming a donor. There was also a section describing what to expect leading up to surgery and afterwards—specifically, the risks involved for the donor. These risks were described as “small and manageable,” which turned out to be somewhat of a comical preface to the list therein: pain, infection, blood clotting, collapsed lung, allergic reaction to anesthesia, and death [13]. For any person inflicted with any of these things, they would be neither small nor manageable. Rare, perhaps, but certainly not small and manageable. The long term health consequences of certain types of donations were also enumerated.

3. Sites that Cater to the Emotions

Whether for good or for ill, there are several sites on the internet which advertise an individual patient’s organ needs. Just three of many examples will be mentioned here, but their content would seem representative. EveretNeedsALiver.com is one such site posted by the friends and family of Everet Barrington, who is described as a friend, a father, a husband and a man who dreams to also be a grandfather one day. That’s not very different from many 47 year old men with a loving wife and a grown daughter. What makes Everet Barrington different from other husbands and fathers is that he is not only dreaming of the future…he’s praying he’ll live long enough to be there when the day comes that his daughter can say, “Dad, this is your grandson. I think he has your smile” [11].

The aim of such a home page is quite evident: to impress upon would-be donors that Everet is no different from them, and deserves a chance to live just as much as they do. Few people with half a soul could deny that. A similar technique can be seen at the web site for Byron Jones Liver Transplant Search, in which the brother of the patient writes,
Without a transplant, my brother may die. This web page was created in prayerful hope of having a directed liver donation for him...We do not ask to receive an organ already intended to be donated to someone on the waiting list. Rather, we request that someone donate who never seriously considered it until now. You might be that someone. [6]

The fact that the site stresses its intent not to undercut patients on the UNOS list is important to note here. This is one of the main concerns of opponents to web-brokered transplantation, who fear that these web sites will take organs away from those who are already waiting. Proponents argue that it will in fact increase the number of donors overall.

DonationForCynthia.com is a third site which appeals to the emotions of viewers. On the home page is a letter posted by Cynthia’s mother which tells her daughter’s story:

My daughter Cynthia, 25, was diagnosed with renal failure in 1995 at the age of 16. Her health deteriorated rapidly to the point where a kidney transplant was required...One day in 1997 Cynthia became very ill...And a few weeks later received a kidney from me. However, after multiple rejections, in 2000 her donated kidney failed and had to be removed. She was placed on the transplant waiting list. Her blood type is very rare, B+, only found in 7% of the population. Which means that being in the emergency list still would not help Cynthia. We feel she is not going to have enough time for a kidney to become available [9].

Urgency is clearly the objective, as it should be. A multitude of family photographs in the column of the page help to give a face to the name, such that one finds a mother’s plea hard to ignore.

III. How Web-brokered Transplantation Affects the Physician-patient Relationship: Mitzel, Matthews, Ethics, Jacobs

While Denver hospitals are finding themselves in the midst of a heated ethical debate and media frenzy, other transplant centers are adjusting to the idea of anonymous donation a little more smoothly. One center, as described by Heather Mitzel, RN, CNN and Michele Snyders, RSW have been making changes with the physician-patient relationship in their conscious
minds. Mostly in response to an increase in the number of altruistic living donors encountered in the 1990s, this particular transplant center (South Dakota Renal Transplant Center of Avera McKennan Hospital in Sioux Falls, SD) has developed a formal protocol to better serve the needs of their patients [4]. The development of this Anonymous Donor Protocol has been slow and deliberate, wondering whether the risks for altruistic donors might outweigh the benefits of the recipient. However, with five-year survival rates for recipients being much higher with living organs (78.4% compared to 64.7% with cadaveric organs), the center decided these donors were too valuable to turn away without further consideration. The center listed the following conflicting ethical principles major factors in their decision-making: 1) their obligation to help others, so long as the benefits outweigh the risks, 2) nonmaleficence (“do no harm”) toward donors [4]. On the one hand, rates of donor mortality and morbidity were estimated to be 0.03% and 1-10%, respectively [4]. Then again, these are the same risks associated with any living donor, related or not. In addition, the researchers found that “donors themselves rated their psychological, social, and physical health higher than the general US population in seven of eight categories” [4]. In the end, the center decided that the autonomy of their patients—both donors and recipients—gave them the freedom of choice and self-determination, in the face of any sort of paternalism that the center might formerly have imposed.

The protocol itself includes the following steps for screening anonymous donors. First, a brief interview of the would-be donor is conducted by phone. He or she must be confirmed to be at least 18 years of age. An information packet will be sent to them, and after reading it the donor must call the center again to discuss its contents. Upon coming in to the center, the anonymous donor will be given both a psychological and a medical examination before being
ranked and put on a donor waiting list. Up until surgery, the donor will be re-evaluated at specified intervals, but can choose to withdraw at any time. On the day of surgery, the donor will be admitted under an alias to a different part of the hospital as the recipient to help maintain anonymity. A post-surgical assessment will also be made of the donor. Expenses are paid by the recipients’ medical insurance [4].

Exactly how widespread such protocols are is hard to say. Each state has different donor rules, which can be viewed at donatelife.net [2]. According to a 1994 survey by Dr. Aaron Spital, transplant centers nationwide are slowly starting to head in the same direction as South Dakota. Although anonymous donation is by no means a common occurrence in 2005, centers are becoming more open to the idea of non-traditional donations. At the time of the survey, the number of centers willing to accept strangers as possible donors increased from 8% to 15%—and that was ten years ago [4]. It is also interesting to note that while 63% of responding centers considered friends as acceptable candidates, none of the 480 centers surveys felt that way just six years earlier [4]. By both accounts, physicians are beginning to give their patients more choice.

It would seem, then, that things are coming along slowly but surely—at least in some transplant centers. But that still does not tell us what to do about web-brokerage sites, especially those like MatchingDonors.com that charge patients for their services. Many physicians and transplant centers worry, and perhaps rightly so, that use of such sites to find organs will “undermine public faith in the United Network for Organ Sharing list” [13]. In the opinion of Dr. Hanto at Beth Israel Deaconess Medical Center in Boston, “if people direct their organs to people not on the list, then people will no longer have faith that the list is fair”[13].
Patients, on the other hand, hear statements like the one from Dr. Hanto and complain that “doctors [are] playing God” [13]. Patients and donors are incredulous that doctors might refuse them simply because they met on a web site. Karen Traxler, for one, claims that her doctors are denying her “the right to have a good healthy life” by placing such an arbitrary restriction on her donor pool [10].

The two basic principles among medical ethicists are patient autonomy and informed consent [3]. If a patient chooses to receive an organ from an autonomous donor who is well informed of the risks involved, why are these two principles being ignored by physicians in the context of organ transplantation? The risks associated with web-brokerage in terms of abuse are real and should not be ignored, but certainly there are ways to regulate internet use such that these risks are minimized. Opponents of web-brokerage seem to be quickly running out of arguments. As Matthews explains, “it is clear that while opponents want more organs, they don’t want a market for organs—not so much because they oppose such a market as because they oppose markets in general. Paternalistically, they impose their values on everyone else” [3].

The trend toward patient autonomy and informed consent has gone a long way in removing the paternalism that for years has characterized the physician-patient relationship [3]. It is now time to extend this progress to the organ transplantation arena. Until then, patients will most likely continue to take matters into their own hands using the internet, while transplant centers evaluate donors on a case-to-case basis.
CH. 4 REFERENCES

CONCLUSION

Finding a New Equilibrium

There is no doubt that you can find life-saving information on the internet—and that we’re all going to manage our health on the Web someday. Whether you can truly depend on that information or are just playing an elaborate, perhaps risky game of cyberdoctor will depend a lot on the electronic company you keep [1].

~Christine Gorman, Time 3 April 2000

Perhaps Peggy Garves of Albuquerque, NM, in an interview with Christine Gorman (above) said it best when she described the role of the internet in her own health care: “Doctors have to see a hundred patients a day and are too busy to talk to me…The internet helps fill in the blanks” [1]. For most individuals in the United States today, the situation is probably similar; the internet is supplemental to doctors who are still the primary health resource. As a population, however, there may be more to think about here.

Medical care exists on a continuum between total physician paternalism and total patient autonomy. Health care received by an individual may fall at one point on this continuum, while for society it may fall somewhere else. The internet plays a role in both of these placements, and since it is hard to speak generally about the former, the latter may be more productive to analyze. With health care in a state of crisis and patients tired of the way things are being done, the internet offers the “path of least resistance,” so to speak, for society to take.

The topics explored here are just a few examples of some of the possible uses and implications of eHealth. General health information is one of the most pervasive forums of eHealth. Cyberchondriacs and health consumers alike make use of general health information as a resource, although it is widely acknowledged that such information is not something to
turn to in an emergency [1]. In terms of quality, no site is perfect, although the best sites have been shown to share some important qualities. Awareness of bad sites is slowly but surely becoming common knowledge. Physicians can become an integral part of propagating this awareness and guiding their patients to the most helpful and pertinent sites.

Online pharmacies and less-reputable internet drug vendors are similarly as pervasive, and it is important to be aware of their effect on the patient-physician relationship. While the FDA probes Congress for greater authority to regulate online pharmacies and punish sites that peddle medications without a prescription, state officials are also seeking help in shutting down rogue sites. In the meantime, physicians can facilitate the situation by giving their patients correct drug information and participating as much as possible in the development of an online prescription infrastructure.

Getting physicians involved in the online system in a feasible way is crucial. It does not make much sense for patients nationwide to be getting online while their physicians are still computer illiterate and thus largely unaware of what is available from eHealth resources. Steps are being taken to make physician-patient emailing a regular part of daily medical practice, though it is still not where it needs to be in terms of scope, regulation, and compensation policy. While making a diagnosis sight-unseen is not only unethical but also illegal, there is no reason why patients and physicians cannot communicate via the internet—given a satisfactory framework. Making medical records electronic is another major area of activity, but again, the problem lies in low physician awareness of both social and economic implications for EMR. A standardized framework is necessary here as well.

Web-brokered transplantation could be an essay in itself, and though explored only briefly here, it has clear implications for the physician-patient relationship—perhaps on a
more philosophical level than the other chapters. So many more societal issues come in to play when discussing organ transplantation, including religion, medicolegal restrictions, and economics. In addition, transplantation is almost always associated with a life and death situation, and so the stakes are higher. The internet thus becomes more of a player than it might otherwise become. People can do strange things when looking death in the face. Physicians need to acknowledge some of these issues before denouncing altruistic organ donation as something immoral and socially detrimental. What appears to be happening now on the transplantation front is a backlash of paternalism simply because there is a fear of the unknown. If doctors are really have the best interests of their patients in mind, they will work with web-brokered transplantation as a reality and a resource that can be harnessed.

Integration is the key to eHealth in the context of the physician-patient relationship. Since the internet is not going to go away any time soon, using it to our advantage seems to be the best course of action. Finding a happy medium between paternalism and patient autonomy within the context of eHealth is absolutely essential in this so-called “IT Decade.” Adjusting to a new equilibrium will require hard work and input from all sides. The ultimate goal of all who are involved in this project should be to bridge the gap between physicians and patients on the internet, such that both parties feel that the system is working for them in a way that is healthiest for all. This is the direction in which health care is headed. It may be the internet—at least in part—which will help to mitigate the health care crisis and provide a tool towards its resolution. Looking ahead toward a new era of cybermedicine, web-based health care may not only help to mitigate the managed care crisis, but may also bring about some real and positive changes to the physician-patient relationship.
CONCLUSION REFERENCE

1. Gorman, Christine. The web docs: The internet can fill the gaps in your medical knowledge. But you need to know how to separate the good sites from the bad. *Time* 3 Apr 2000.