

Introduction

Every day, millions of Americans use the Internet to search for health information. They inquire about specific diseases, treatments or procedures, diet/nutrition, exercise and fitness, medicines, alternative medicine, health insurance, and other related information [22]. This paper explores consumer access and use of online information. Who is using the Internet to search for health information? How are they using it? What do they do with the information they find? And what are the barriers to information access? I examined numerous studies that addressed these questions, and found a plethora of answers, with a lot of common ground. One of the threads that permeated the literature was concerns and questions on the quality of online health information and how to know what to trust. What is the quality of the information available? What factors influence consumer trust in the information they find? And what efforts are underway to address quality and trust? After exploring these issues, it became clear that better methods are needed to identify quality sites and ensure they come to the attention of consumers, so further research is needed to clarify criteria for quality and technical mechanisms to aid the consumer in reaching the quality sites.

General Statistics

A 2004 survey by the Pew Internet and American Life Project [22] indicated that approximately 128 million Americans age 18 or older are online, or about 63% of the adult population. On a typical day, 70 million Americans log on, but only 7 million of them do so to get health or medical information. This figure negatively distorts the impact of online health information, though. Pew found that 93 million Americans (~70% of those online) have used the internet for health or medical purposes at least once. The 2004 US Department of Commerce study *A Nation Online* [27] indicated about 40% of online users sought health information. A

consumer survey by Baker et al. [2] conducted in 2001-2 indicated that about 40% of internet users in their study had searched for health information in the past year, and approximately 25% had done so at a frequency of every 4 months or greater. From these studies, it appears that seeking health information is a relatively infrequent activity that a lot of online consumers engage in. This has implications in terms of their experience with conducting health searches, which will be discussed further in the *Consumer Behavior* section.

Interestingly, the Pew information on a typical day indicates the number of consumers conducting health searches has not grown substantially since 2000 when compared to other types of searches (16% for health searches vs 50-84% for most other searches). The Commerce report corroborates, with about 18% growth in health searches since 2001. It is unknown why health searches have not grown as substantially as other searches, however the remainder of this report provides ample evidence for barriers for health seekers that may be contributing factors.

While the Internet has gained widespread popularity in the U.S., access is not uniform. For example, while three quarters or more of individuals age 18-49 are online, only 25% of those 65 or older go online. Other demographic groups with less than a majority online include non-hispanic blacks (43%), those with a household income less than \$30,000 per year (44%), and those with less than a high school education (32%). Marginal majorities exist for those with a high school education (52%) and those living in rural areas (56%). These disparities have implications for consumers' ability to gain the advantages of anytime, anywhere access to health information. Indeed, some of the populations with the least access are those with the greatest health needs (eg, low-income seniors).

Disparities of behavior exist for those with broadband vs. dialup access. About 60 million Americans (47% of those online) have a high-speed connection, and these users are

online longer, more frequently, doing more things; they report higher satisfaction with the role the internet plays in their lives. Commerce's *A Nation Online* report [27] indicates that broadband usage is lower in rural areas. Pew reports that broadband is far less prevalent for lower-income users: while 55% of those making \$>100,000 have broadband access, only a quarter of those earning less than \$50,000 a year do, and the numbers drop precipitously at the low end of the scale. The Commerce report studied health seekers specifically and found that ~48% of broadband users searched for health information, vs. 40% of dialup users and 32% of users with no Internet at home, so broadband access increases consumer's health-seeking behavior.

Not all consumers seek health information to the same degree. According to Pew, women are more likely than men to seek health information (85% vs. 75%) and middle-aged people (30-64) are more likely than the young or seniors to look for online medical information (70% vs. 57%). Pew points out that these statistics are not unique to the Internet environment, and to some extent mirror consumer behavior offline: people bring their existing interests and activities to their online experience.

Consumer Behavior

Several studies have been conducted to assess how consumers access online information, and what they do with the information they receive. Many of these are consumer surveys.

Anderson [1] conducted a U.S. consumer survey in 2002 to identify patterns of use of online health information, as well as barriers to access. His data indicate that consumers are primarily using the internet for one-way, general information access. The two most common searches are for information (78%) and to locate providers (36%). Activities involving two-way or personal information were not very common: provider communication (9%), on-line records

(2%), and on-line support (2%). Even though these interactive activities were uncommon, they are desired by consumers: 56% expressed a desire to communicate with providers, 62% of those with a chronic disease expressed a desire to use the Internet to chart their health status, 22% of consumers would like on-line medical records, and 23% were interested in on-line support. The respondents indicated several barriers to use of the Internet: threats to privacy (39%), problems evaluating quality (29%), physician disapproval (26%), inaccuracy (18%), and unreliability (13%). These items are recurring themes in the other studies reviewed in this paper.

Pew studies from 2001-2002 [16] indicated a higher usage of online support groups than the Anderson study of the same time period (19% vs. 2%). Even so, the numbers remain a minority of the online population. Pew's consumer wishlist supports Anderson's findings, indicating preferences for electronic medical records and test results and doctor-patient email; it also identifies two other desires, information closed to non-subscribers and information on a doctor's background. In addition, they identified two types of information consumers want that are already prevalent on the Internet (drug interactions and diagnostic tools or symptom finders) indicating that consumers do not always find what is already available to them.

The aforementioned consumer survey by Baker et al. [2] revealed some interesting information on the patient's perceived effects of the health information they find online. Table 4 from his report is reproduced below. This study confirms some things that were predicted, such as that online health information would improve consumers' understanding of symptoms, conditions, or treatments. It also provides evidence that some fears are not true (or not true yet): only 30% of respondents agreed or strongly agreed that the use of the Internet or email had improved their ability to manage their healthcare needs without visiting a doctor. Apparently, they are using the Internet as an adjunct to doctors visits. Also, note that very few of them are

finding information to assist them in seeking care from a different doctor. Regrettably, the Internet is having only a minor effect on the way consumers eat or exercise.

Table 4. Perceived Effects of Internet or E-mail Use on Health Care Understanding and Decisions*

Effect of Using the Internet or E-mail	No. of Respondents	Agree or Strongly Agree, Weighted %
Among Respondents With None of 5 Chronic Conditions		
Improved my understanding of symptoms, conditions, or treatments in which I was interested	1119	67
Improved my ability to manage my health care needs without visiting a doctor or other health care provider	1112	30
Led me to seek care from different doctors or other health care providers than I otherwise would have	1104	12
Affected the way I eat or exercise	1115	27
Among Respondents With ≥ 1 of 5 Chronic Conditions		
Improved my understanding of [condition]	1382	48
Improved my understanding of possible treatments for [condition]	1378	46
Improved my understanding of other symptoms, conditions, or treatments in which I was interested	1396	58
Affected treatments I am using for [condition]	1364	16
Improved my ability to manage my [condition] by myself	1359	27
Improved my ability to manage other health care needs without visiting a doctor or other health care provider	1375	30
Led me to seek care from different doctors or health care providers for [condition] than I otherwise would have	1360	7
Affected the way I eat or exercise	1370	32

*Questions were asked of those who said that they had used the Internet to look for information or advice about health or health care; used e-mail or the Internet to communicate with a provider, friend, family member, or other person with similar health care concerns; or used the Internet for any purpose related to prescription drugs. The full question preamble was, "Thinking overall about all of the times in the last year that you used the Internet or e-mail for things related to health or health care, to what extent would you agree or disagree with the following statements? Using the Internet or e-mail . . ." Response choices on a 4-point Likert scale were strongly agree, agree, disagree, strongly disagree. Condition was specified as heart problems, diabetes, cancer, hypertension, or depression based on the chronic condition(s) the respondent indicated. Sample sizes are unweighted; percentages are weighted.

Eysenbach and Köhler [13] conducted a study using focus groups, usability tests, and in-depth interviews to understand better how consumers search for online health information. This study differs from the others in that it actually observes consumer behavior, versus just asking them what they do. They found that consumers usually were successful at finding health information in under 6 minutes. It revealed that they spent little time on any single website (under a minute). They used general search engines as their starting point (not medical portals or libraries). They also used suboptimal search techniques (for example, a single search term).

Most of them (71%) clicked on one of the first five search results returned by the search engine.

Several other studies reviewed for this paper corroborate that consumers use general search engines and simple search techniques [12, 20, 24].

One result from Eysenbach's study was particularly interesting: while participants in the focus groups stated that they were assessing the credibility of the websites they visited (they said they looked for the source via the *about us* feature or a HONCode logo), they were not observed to do so in the usability studies. In fact, when asked in focus groups to provide the source of the information they retrieved, they recalled the source for only 21% of the searches.

Cain et al. [8] conducted U.S. consumer surveys in 1999-2000 and concluded that there are 3 types of health seekers: the well, the newly diagnosed, and the chronically ill. These groups use the Internet very differently, suggesting there may be a need to differentiate services. The well (about 60% of health seekers) search for preventive wellness information, and perform episodic searching about short-term acute illnesses. They also purchase consumer care products online, such as health and beauty aids, vitamins, herbals, and alternative medicines. The newly diagnosed (about 5%) perform very intensive searching for specific information, and they do a lot of searching in a short period of time. They also take advantage of 24 hour access to experts and online support groups. The chronically ill and their caregivers (35%) perform regular searches, use keywords, and do relatively little "site hopping." They make strong use of online chat and sharing of anecdotes, and they are the heaviest users of online commerce. This study also noted that 2/3 of online health consumers are concerned about privacy, and that populations with higher disease incidence (minorities, poor, older people) are less likely to be online.

Dickerson et al. [12] conducted a survey of patients at 3 Urban clinics—a private hospital caring primarily for the working insured and retired patients, a university training

hospital, and a public clinic serving mainly poor uninsured patients. They chose this population in part to determine whether a digital divide exists in their patient population. This study differs from the others in that it studied actual patients in the clinical setting. They found that 13% of online patients search for health information prior to a doctor visit, while 43% accessed information after a doctor visit. 45% searched for information unrelated to their visit (Eysenbach's study also found that participants used the information they obtained either to confirm what the doctor told them or to take it to the doctor for verification).

The Dickerson study found that patients with commercial insurance were more likely to search the Web for health information, and that education level influences Internet use; they suggested that supporting education could have wide-reaching effects on promoting health. The most interesting finding of the Dickerson study was that 30% of patients *with* Web access relied on other people to perform their searches, and 22% of patients relied on friends and family to gain access to the Web. These findings imply some level of digital divide may be at play.

Two studies surveyed physicians to determine the impact of online health information on the physician visit. Murray et al. [19] studied US physicians in 2000-2001 and found that 85% had a patient bring Internet information to a visit; however, the majority said that less than a fifth of patients do so. These physicians indicated that 18% of the information brought to them was very relevant, and 64% somewhat relevant. The vast majority rated their patients as only fair or poor at appraising information quality. It would be interesting to ascertain whether any of these physician perceptions are biased due to their role. The majority thought the internet information had a positive (38%) or neutral (54%) effect on the physician-patient relationship; however, they reported that patient questions regarding the information were making visits less time-efficient. Physicians saw a negative effect on the physician-patient relationship if the patient challenged

their authority, requested inappropriate treatment, or if the physician did not do what the patient wanted. Most physicians believed the internet information made no difference to the quality of care or health outcomes. Despite this, the majority of them thought the increase in online health information was a good thing, and most (77%) encouraged patients to search online. A much smaller number (35%) provided their patients with URLs.

The second physician survey was conducted by Potts and Wyatt [21] in 2001 and studied UK physicians. They reported a much lower prevalence of Internet information, indicating 1-2% of patients used it, but also noted that some of the doctors indicated they did not know what their patients were doing. Similar to the US survey, they found that the doctors thought the information was usually (20%) or sometimes (48%) reliable. Eighty-five percent reported patients experiencing benefits, and 44% reported patients experiencing problems from online health information, with 8% physical harm. Some of the problems reported included ordering dangerous or ineffective drugs, getting misleading second opinions or risk estimates, misleading advice from online support groups, or spending a pathological amount of time online. Most physicians (87%) also reported problems for themselves, such as longer consultations (64%) and more unnecessary investigations (44%). However, they also reported benefits for themselves (70%), although those were unspecified in the study report.

Issues and Barriers

Cline and Haynes [9] conducted a literature review in 2001 that summarizes much of what is known about issues and barriers to accessing online health information. Barriers to access include technical barriers (such as not having internet access), language barriers (most

online information is in English, but not all people speak English¹); and literacy barriers (both computer literacy and reading literacy). Other factors are information overload from the sheer volume and disorganization from the Internet's decentralized nature. Varying competencies in searching techniques impede consumers' ability to efficiently locate health information, and this factor is compounded by the aforementioned volume and disorganization. In addition, information may not be targeted for the audience (eg, AIDS information for treatment options in Africa vs. USA). Another significant barrier is that the language of health information tends to be very technical; reading levels of the material often exceed general literacy levels. Usability issues also impact retrieval, as many websites are of poor design. Other issues include a lack of permanence of online information and a lack of currency (ie, materials may not be updated frequently and the date of update may not be displayed).

Cline and Hanes also identified a set of hazards for online health information seekers. The lack of peer review or regulation places the burden of evaluating accuracy and quality on the consumer. Information online can be inaccurate or misleading; it may contain assertions that are dangerous or life-threatening if heeded, or information may be incomplete and omissions equally dangerous (online support groups were found to have particularly high levels of inaccurate or unsupported information). Consumer's evaluation skills may be inadequate, or they simply may not be attuned to the need to assess quality; hence, they may fail to recognize key information is missing, that information is biased, or that evidence is lacking to support the claims. It may be difficult for the consumer to distinguish the snake oil salesman from the bona fide.

Cline indicated studies have shown online information may contain risk-promoting messages, such as providing information about suicide methods or sexual solicitations to young

¹ Eysenbach's study demonstrated that even those who speak English as a second language may experience the language barrier: the English-speaking German participants in his study failed to use English search terms in their queries.

people. So, too, there is concern about online pathologies—Internet addiction itself, as well as that individuals with serious psychiatric disorders may find validation they are “normal” through online interactions with like individuals; and websites promoting abnormal behaviors may cause an increase in the prevalence of these disorders.

Crocco et al. [10] conducted a systemic review of peer-reviewed literature to ascertain just how much harm was occurring due to online health information. They identified only three articles that described harm, however, they expressed skepticism as to whether the prevalence of harm is truly this low, or perhaps is underreported. One article described 12 cases of emotional distress derived from irrelevant information retrieved due to inappropriate search strategies. Another article described phenol poisoning in dogs after the owner obtained inappropriate information about using phenol to treat heartworm. The third article described a man with skin cancer who identified an alternative cancer treatment that he purchased online, resulting in hepatorenal failure, from which he died. The UK survey of physicians by Potts and Wyett [21] also indicated a low prevalence of harm, with 3 or possibly 4 deaths reported by several hundred doctors in response to a question with no timeframe, thus reflecting their experience over many years. The risk seems higher, however with alternative medicine sites. Walji et al. [28] analyzed 150 alternative medicine sites and determined that 25% of the sites contained statements that could lead to direct physical harm if applied (eg, advocated treatments that could be toxic or cause interactions with conventional therapies), and 97% of them omitted information where the omission could cause harm (eg, contraindications or adverse reactions).

Both seniors and the disabled are affected by the inverse information law: access to appropriate information is particularly difficult for those who need it most. Online information could bring independence if the information is made accessible. Studies conducted by Becker

[3] and Zeng and Parmanto [29] revealed physical barriers to online access. For seniors, vision changes can affect their ability to read small print, their reading speed, comprehension, and navigation abilities: small font sizes on websites (especially when not adjustable) can impede access to information. Declines in cognitive abilities, such as working memory and problem solving can also be a factor: websites with complex navigation schemes, cluttered pages, or poorly designed search can have a negative effect. Even decreases in motor skills can make mousing difficult, so small pull-down menus are challenging. For the disabled, Zeng noted that they use the internet at a quarter the rate of other people (9.9% vs. 38.1%), and that Nielsen (2001) reported the usability of the Web is 3 times better for users without disabilities. Zeng studied 108 consumer health websites for their adherence to two accessibility standards². They found that none of the websites was absolutely accessible. The most frequent violations included failure to identify the language of the text, provide summaries for tables, or use relative size/positioning. Government and educational sites were more accessible. Zeng also found that accessibility correlates with popularity, suggesting that resources invested into better serving the disabled may attract more users to the site.

Berland et al. [4] compared Spanish and English search engines and health websites. They found that the majority of links returned by search engines (80% for English, 88% for Spanish) did *not* lead to relevant content. All of the English sites and 86% of the Spanish sites were written at a 9th grade reading level or above, which is beyond the recommended reading level for the general consumer. For the English sites, 63% were at or above a *college* reading level. About half of health information on English sites studied was commercialized vs. about a fifth of Spanish sites. Information was found to be incomplete but generally accurate, with

² The World Wide Web Consortium Web Content Accessibility Guidelines and the US Access Board Electronic and Information Technology Accessibility Standards (per Section 508 of the Rehabilitation Act Amendments of 1998).

English sites lacking information on about 1 in 4 topics, while Spanish sites lacked coverage on half the topics and information was less consistently accurate.

Kalichman et al. [18] studied the impact of the digital divide in the context of HIV/AIDS care, noting that minority and low-income individuals do not view the Internet as relevant in their daily lives. An important finding was that those who accessed online health information had a greater understanding of their disease, treatments, and the importance of complying with medication schedules. Fifty percent of those who accessed online health information had undetectable viral loads compared to 28% of those who did not go online. They noted barriers to access for those who are not experienced internet users, indicating that providing computers is not sufficient to bridge the divide: public access terminals have waiting lists and time restrictions that may mean insufficient availability for conducting health searches; individuals lack skills for searching, navigating, sorting, filtering, and using information, and they are slowed down by their lack of familiarity with the keyboard and basic computing functions; they have difficulty spelling medical terminology, and they experience a general level of anxiety and discomfort with the online environment. By conducting theory-based training, Kalichman demonstrated that search skills could be improved for even the most disadvantaged users with minimal exposure and encouragement. Crowell [11] conducted studies of spelling suggestions and came up with methods to improve the odds of a correct spelling suggestion in the number one spot by 63%. More studies such as these are needed to bridge the digital gap.

Bhavnani et al. [6, 7] conducted studies on the distribution of healthcare information and search strategies used by experts. They found that in order to gain comprehensive information (starting with high quality pages on a health topic), a user must first visit more than one general page for an overview of the issue (getting a lot of facts in medium detail), then they must visit

specialized pages for in-depth specifics (getting a few facts in a lot of detail). He also found that domain-specific knowledge exists for expert searchers, including goal sequencing strategies and knowledge of important URLs. General purpose search engine results do not make domain-specific knowledge easily accessible to the user, and novice searchers do not have this knowledge. The latter finding is of particular import given that other research indicates general purpose search engines are the primary “way in” for the consumer.

Slater and Zimmerman [19, 20] studied the characteristics of the first 10 health-related websites identified by 5 common search engines, and found that only 35% of those websites were non-promotional and science based, while another 11% were science based and selling product. The remaining majority were either non-science-based selling product (22%) non-science-based nonpromotional (1%) or miscellaneous book catalogs, personal pages, or unavailable sites (31%). Only 3% of the first 10 sites were government-sponsored. Site listings returned by the search engines identified the organizational sponsor only 47% of the time, and 23% of the websites selling products were not identifiable as such from the site listings. They indicated that a large majority of commercial sites were found to promote unregulated supplements and unproven remedies and services, reflecting a “buyer beware” marketplace.

Assessing Quality and Trust

Since so much of the above literature mentions concerns over the accuracy or quality of online health information, this topic deserves more in-depth exploration. Numerous studies have evaluated accuracy and quality, and several professional organizations and standards bodies are attempting to establish criteria on which to base quality assessments. Nonetheless, straightforward methods of assessing accuracy and quality remain elusive. Meanwhile, some interesting studies have shed light on consumer trust and mistrust.

Sillence et al. [24] conducted an observational study of women in various stages of menopause. They found that consumers appraise websites differently from experts. For example, experts recommended menopause-related pharmaceutical sites as highly accurate, but consumers distrusted them as biased for commercial gain. Also, consumers tended to trust information provided by someone like them—ie, other women going through menopause were considered trusted sources on menopause. Sillence used Briggs et al's model of 3 stages of trust development as the basis for evaluating how consumers establish trust: stage 1 is a rapid screening using heuristics to reject items; stage 2 is an in-depth evaluation using analytics to accept items; stage 3 establishes an ongoing long-term relationship. Sillence found that in stage 1 consumers rejected sites primarily for design issues (94%), such as an inappropriate name, busy layout, inadequate navigational aids, popup ads, or a corporate look (this finding was echoed in some of the other studies [9, 13, 14]). These factors were less critical to experts. In stage 2 consumers selected sites for in-depth evaluation primarily on content factors (83%), such as it had informative content, relevant illustrations, a variety of topics, unbiased information, used clear simple language, and source/credentials were explicit. The study of stage 3 long-term relationships is in progress. This study suggests that attention to site design is critical to getting noticed by consumers, who might rule a site out regardless of its content if the design issues are too significant.

Bernhardt and Felter [5] examined trust issues via a focus group of new mothers, who indicated that sources and motives should be clear in order for them to trust the content of a website. The most trusted sources were physicians and nurses. Domain also affects perceptions of trust, with *.edu* more trustworthy than *.com*, for example. [Similarly, Fallis and Frické found that *.org* correlated with accuracy—see below for further details]. They also found that

experience breeds trust: new mothers trusted clinicians to provide clinical information, but were more trusting of other parents to provide parenting advice. Bernhardt found that perceived trust can increase with exposure: a new mother who saw the same doctor's name turn up repeatedly found that source more trustworthy. Contradictory experts can erode trust: if they cannot agree why should the new mother trust their advice? On the other hand, repetition and convergence of advice led to trust when found repeatedly at multiple sites, or across internet advice, doctor advice and advice from other parents.

Cline's literature review [9] identified the following criteria as important for evaluating quality and establishing trust: source characteristics (how authoritative and trustworthy); message characteristics (how current, accurate, organized, readable and intelligible); audience characteristics (is the site targeted to its audience); and peer review/rating systems (to provide some sort of quality or trust certification).

Eysenbach et al. [14] conducted a systemic review of the literature studying health website quality to determine whether a set of quality criteria would emerge. After screening 8000 relevant citations, they identified 79 studies that met the inclusion criteria for their evaluation. Those 79 studies assessed ~6000 health websites and identified 86 quality criteria. The most frequently used criteria were accuracy, completeness, readability, design, disclosures, and whether references were provided. Interestingly, both Cline and Eysenbach identified design and readability as valid criteria according to experts; however, Sillence did not perceive experts as being concerned with those criteria. Perhaps consumers are less divergent from experts than it seemed. Eysenbach concluded that a lot more work is needed to come up with operational definitions of quality criteria, and that comparisons across studies were extremely difficult. Even so, 70% of the studies concluded that quality is a problem. Eysenbach cautioned against

negative bias toward the web, though—he indicated that other studies have shown that as much as 70% of information broadcast on TV is inaccurate, misleading or both; and 30-55% of information in magazines and newspapers is inappropriate. In contrast a study of telephone inquiries to libraries on health topics found only 3.6% inaccurate responses, a strong justification for continued funding of libraries.

Fallis and Frické [15] conducted an empirical evaluation of the accuracy of websites on the treatment of fever in children. They defined accuracy as both correctness and completeness, and used simple search engine queries to identify websites to evaluate. They relied on proposed accuracy indicators published in guidelines on evaluating the quality of health information. The results yielded 3 indicators that correlated with accuracy: the display of the HONCode logo was 4 times more likely on accurate than inaccurate sites; having a *.org* domain was 2 times more likely for accurate sites; and displaying a copyright was 2 times more likely to be *absent* on inaccurate sites. They also found that many proposed indicators did not correlate with accuracy, including whether the author is identified and whether the author had medical credentials. Likewise, lack of currency and presence of advertising did not correlate with inaccuracy. Fallis emphasized that the presence of an indicator is not a guarantee but a probabilistic relationship; there is also no guarantee a current indicator will retain its value over time; for example, copyright is not a robust indicator, as it is easy to fake. Also, currency may not have shown up as an indicator partly because the treatment of fever has been stable for years.

Risk and Dzenowagis [23] reviewed 13 national, regional, and international quality initiatives. Their review arrived at 10 conclusions:

- 3 key *mechanisms* identified and needed: codes of conduct, third-party certifications, tool-based evaluations.
- Successful quality program *elements*: health information criteria, educated/interested citizen, credible enforcement

- Current initiatives reveal many *gaps*—the most serious are the excessive burden placed on citizens and cost of implementation
- More *research* is needed to address quality of content, context & relevance, instruments for enforcement
- Needs of developing world and *info-poor* urgently need addressed
- No mechanisms exist for ensuring quality relative to *pseudo-health* [quacks and frauds]
- No mechanisms exist for ensuring quality of *alternative medicine* [legitimate treatments]
- *Language* (tongue and syntax) remains a major obstacle
- Need to coordinate and *harmonize* efforts
- Concerns and *criticisms* against establishing models of governance are not well-reasoned.

They asserted that clear, credible, trusted leadership is needed on a global scale in order to better resolve the quality issue for online health information. The above summary correlates well with the other studies reviewed for this paper.

Given the above considerations, and the repeated mention of the HONCode in other studies, it is useful to evaluate this, one of the older and more prominent codes of conduct, and the Health on the Net (HON) Foundation's other activities in improving consumers' access to quality health information. According to their website (www.hon.ch), the HONCode [17] was begun in 1996, and is a voluntary accreditation system and seal that is applied to accredited sites. Currently 4,000 sites are accredited by HON. HON accredited sites display the HONCode logo, and clicking on the logo launches a window with information about the site (see Figure 1). While HON does not monitor the sites for compliance with the HONCode principles, it does offer a self-monitoring reporting mechanism for filing complaints, and it will remove the link to the HON site if a website fails to correct the problems. The HON principles address authority, complementarity (supports rather than replaces physician-patient relationship), confidentiality, attribution, justifiability, transparency of authorship, transparency of sponsorship, and honesty in advertising and editorial policy.

HON offers several other tools for consumers, including HONSelect, a multilingual metasearch engine that uses NLM MeSH terminology, limits searches to medical and health

topics and offers a keyword or classification scheme search. Results provide definitions, synonyms, narrower terms, and related terms, as well as related websites and a wealth of other information (see Figure 2). MedHunt, a specialized search engine, and MARVIN (HON's medical spider) work in tandem to provide query results that are pre-selected to be relevant to the health domain, as well as provided in a context that enable the consumer to evaluate quality (see Figure 3). For example, the search listings indicate whether the site is HON certified, if it is commercial or not, its country of origin, related keywords, and the last time it was visited by MARVIN. These tools from HON are examples of how to provide better services to consumers. The only problem with their approach is that based on what we know of consumer behavior, they may never discover or use these search tools unless the HON website shows up in the first few hits on a general search engine query.

Conclusions

Based on the information contained in the above studies, a number of conclusions can be drawn about both consumer behavior and the technologies and content available to them.

Consumer Behavior

- Consumers search for health information infrequently.
- They use general purpose search engines (rather than medical portals).
- They use very basic querying techniques (1-2 words).
- They select to view links from the first 1-10 items in the searchlist (often the first five).
- They spend little time at an individual web site (less than a minute).
- While concerned about quality and credibility issues, they sometimes do not evaluate the quality or credibility of the sites they select.
- They generally seem to use the web as an adjunct to doctor visits, not as a replacement.
- Not everyone has equal access to health information online.

Since searching for health information is not a daily activity for consumers, their opportunity to become expert health seekers is somewhat limited. Better tools are needed to help novice searchers navigate more effectively and successfully. Any technical solutions that are

provided should take into consideration the above assumptions to remain relevant. For example, the tool could be incorporated into the general purpose search engine, or it could appear at the top of search engine results; otherwise, the average consumer will not be aware of its existence.

Doctors are currently still a very relevant source of health information for the consumer. Physicians have traditionally provided pamphlets and other literature to patients at their visits. This literature could be used to improve consumer search behavior by providing the domain-specific knowledge of the expert health seeker (search steps, sequencing, and urls), thereby steering the consumer to reputable and trustworthy online information.

Continued advocacy is needed to illustrate the impact of the digital divide on consumer health and to overcome those barriers. Further studies should be conducted to build upon Kalichman's concrete evidence tying online access to improved patient outcomes for HIV/AIDS. Studies such as these could support proposals to better serve the under-connected and those with low literacy (both technical and traditional).

Technologies and content

- There is considerable variability in accuracy and quality of health-related websites.
- Some websites contain potentially harmful information.
- Websites often fail to provide complete information.
- Many search results are irrelevant.
- Retrieval algorithms do not necessarily favor quality sites.
- Search engines do not provide any way to assess a link's quality or trustworthiness in the hitlist brief descriptions.
- There is no consensus yet on how to establish quality.
- Quality initiatives such as HON can have an impact.

In the distributed, organic world of health information on the Internet, it would be fruitless to assume we could force order on the chaos by requiring the multitudes to improve the quality of what is available: the likelihood of success would be very slim. Rather, we should assume variable quality, and technical solutions should focus on ways to make quality more

apparent despite the chaos. In order to achieve that, social solutions are also needed, in the form of better quality criteria to establish the foundation for accreditation and codes of conduct.

Improved clarity in what constitutes quality would allow legitimate health web developers to improve the content of their sites in order to gain accreditation. It would also lay the foundation for better technical solutions that could derive improved ranking algorithms and heuristics, providing improved relevancy as well as more informative search result listings from the quality criteria and accreditation mechanisms. Thus, web developers would be encouraged to adhere to a minimum set of standards; improved transparency of quality would provide mechanisms for improved hitlists; and the frauds and quacks would become more apparent by the absence of a trustmark and their nonconformance to established and recognized quality criteria.

Opportunities abound for research to support the above conclusions. In particular, research should be designed to answer the question of how to improve the accuracy, completeness, and trustworthiness of the top 10 hits returned by generalized search engines, since that is the starting point for most consumers. Another area that could prove fruitful would be to determine ways for the accreditors to automate as much of the quality assessment as possible (once criteria are established), since accreditation is only sustainable if they have the resources to sift through the masses of data.

Online health information is becoming an integral part of consumer research on healthcare issues. So much has already been accomplished by making this information available directly to the consumer. And yet, as these studies have demonstrated, there is a long way to go for online health information to be available effectively in a trustworthy manner. Fortunately, many researchers are studying the issues to come up with better solutions for the future.

Figure 1 HONCode Certificate screen



The screenshot shows the HONCode Certificate screen for the website 'Wrong Diagnosis'. At the top, there is a blue banner with the HONcode logo on the left and the Health On the Net Foundation logo on the right. Below the banner, the text 'HONcode application status:' is followed by a red HONcode logo and the text 'Wrong Diagnosis is in compliance with the HONcode'. A table below lists the site details:

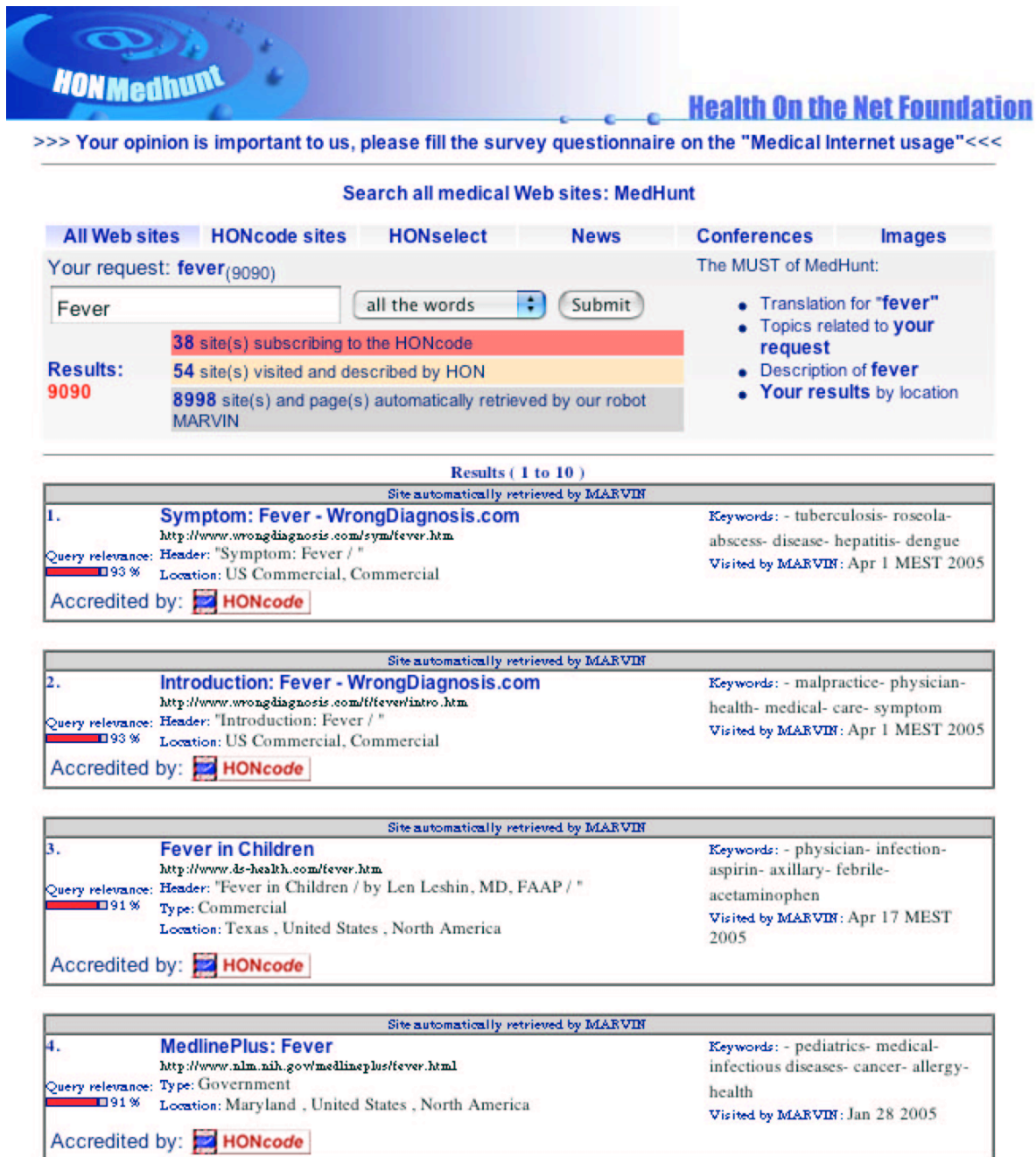
Title of the site:	Wrong Diagnosis
Web address:	http://www.wrongdiagnosis.com/
HONcode PIN number :	HONConduct577616
Date of initial review:	30 Mar 2003
Date of last subsequent review:	08 Oct 2004

Below the table, a paragraph states: 'This **certificate** confirms the revision of the site by the HONcode Team at the above date. It respects and pledges to honor the **8 principles of the HON Code of Conduct** (HONcode).' Below this is a search bar with an 'Accredited' badge, the text 'HONcode', and the prompt 'Search only accredited sites!'. A link below the search bar reads: 'Download the free HONcode Toolbar: [Automatic verification of the accreditation status of health/medical websites.](#)' At the bottom, there is a navigation bar with links for 'Principles', 'Search HONcode sites', 'Complaints', and '© Health On the Net Foundation'. A dropdown menu is open under 'Principles', showing 'in English'.

Figure 2 HONSelect Search Example

The screenshot shows a web browser window with the URL <http://debusssy.hon.ch/cgi-bin/HONselect?browse+C23.888.119.344>. The page title is "Fever - Hyperthermia - information page with HONselect". The browser's address bar shows the URL and a search icon with the text "Google". The page content includes a navigation menu with links for "SI", "Yahoo!", "News", "UofM", "IM", "Ann Arbor", "CIC Web", "CIC", "SI projects", "General", "job stuff", "Media", and "cyber-state". Below the navigation menu is a banner for "HON Select" and "Health On the Net Foundation". A survey prompt reads: ">>> Your opinion is important to us, please fill the survey questionnaire on the 'Medical Internet usage'<<<". The main content area is titled "Search 33'000 medical terms with HONselect" and features a search bar with the word "Fever" entered. Below the search bar are tabs for "All Web sites", "HONcode sites", "HONselect", "News", "Conferences", and "Images". The search results for "Fever" are displayed, including a definition: "An abnormal elevation of body temperature, usually as a result of a pathologic process." and a list of synonyms: "Hyperthermia / Pyrexia / Fevers / Hyperthermias". The page also lists narrow terms like "Fever of Unknown Origin" and "Sweating Sickness", and a "See also" section with links to related terms such as "Malignant Hyperthermia", "Anti-Inflammatory Agents", "Heat-Shock Proteins", "Hyperthermia, Induced", "Pyrogens", and "Body Temperature". The page footer indicates "MeSH 2001 © National Library of Medicine®" and provides a "Browse - New search" link. Below the search results is a section titled "Web resources for 'Fever'" with a table of links and domain names. The table lists various resources, including "HONcode - Symptom: Fever - WrongDiagnosis.com" (www.wrongdiagnosis.com) and "HONcode - eMedicine - Typhoid Fever : Article by Roberto Corales, DO" (www.emedicine.com). The table also includes a "next results" link. Below the table is a section for "Narrow term(s)" and "See also" with links to related terms. The page also features a "Medical image(s) for 'Fever'" section with a "Browse - New search" link and a "Medical News for 'Fever'" section with a link to "Experience Counts in Treating Baby's Fever (03/09/2004, HealthDay)".

Figure 3 MedHunt Search Example



HONMedhunt Health On the Net Foundation

>>> Your opinion is important to us, please fill the survey questionnaire on the "Medical Internet usage" <<<<

Search all medical Web sites: MedHunt

Your request: **fever** (9090)

Results: 9090

- 38 site(s) subscribing to the HONcode
- 54 site(s) visited and described by HON
- 8998 site(s) and page(s) automatically retrieved by our robot MARVIN

The MUST of MedHunt:

- Translation for "fever"
- Topics related to **your request**
- Description of **fever**
- **Your results** by location

Results (1 to 10)

Site automatically retrieved by MARVIN

1.	Symptom: Fever - WrongDiagnosis.com http://www.wrongdiagnosis.com/sym/fever.htm Query relevance: Header: "Symptom: Fever / " 93 % Location: US Commercial, Commercial Accredited by:	Keywords: - tuberculosis- roseola- abscess- disease- hepatitis- dengue Visited by MARVIN: Apr 1 MEST 2005
2.	Introduction: Fever - WrongDiagnosis.com http://www.wrongdiagnosis.com/fever/intro.htm Query relevance: Header: "Introduction: Fever / " 93 % Location: US Commercial, Commercial Accredited by:	Keywords: - malpractice- physician- health- medical- care- symptom Visited by MARVIN: Apr 1 MEST 2005
3.	Fever in Children http://www.ds-health.com/fever.htm Query relevance: Header: "Fever in Children / by Len Leshin, MD, FAAP / " 91 % Type: Commercial Location: Texas , United States , North America Accredited by:	Keywords: - physician- infection- aspirin- axillary- febrile- acetaminophen Visited by MARVIN: Apr 17 MEST 2005
4.	MedlinePlus: Fever http://www.nlm.nih.gov/medlineplus/fever.html Query relevance: Type: Government 91 % Location: Maryland , United States , North America Accredited by:	Keywords: - pediatrics- medical- infectious diseases- cancer- allergy- health Visited by MARVIN: Jan 28 2005

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