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Original Paper

# How Adolescents Use Technology for Health Information: Implications for Health Professionals from Focus Group Studies

Harvey Skinner[1], PhD; Sherry Biscope[1], MHSc; Blake Poland[1], PhD; Eudice Goldberg[1,2,3], MD

[1]Department of Public Health Sciences, University of Toronto, Toronto ON, Canada
[2]Hospital for Sick Children, Toronto ON, Canada
[3]Department of Paediatrics, University of Toronto, Toronto ON, Canada

**Corresponding Author:**
Harvey Skinner, PhDChair
Department of Public Health Sciences
McMurrich Building, Faculty of Medicine
University of Toronto
Toronto Ontario M5S 1A8
Canada
Phone: +1 416 978 8989
Fax: +1 416 978 8299
Email: Harvey.skinner@utoronto.ca

## Abstract

**Background:** Adolescents present many challenges in providing them effective preventive services and health care. Yet, they are typically the early adopters of new technology (eg, the Internet). This creates important opportunities for engaging youths via eHealth.

**Objective:** To describe how adolescents use technology for their health-information needs, identify the challenges they face, and highlight some emerging roles of health professionals regarding eHealth services for adolescents.

**Methods:** Using an inductive qualitative research design, 27 focus groups were conducted in Ontario, Canada. The 210 participants (55% female, 45% male; median age 16 years) were selected to reflect diversity in age, sex, geographic location, cultural identity, and risk. An 8-person team analyzed and coded the data according to major themes.

**Results:** Study participants most-frequently sought or distributed information related to school (89%), interacting with friends (85%), social concerns (85%), specific medical conditions (67%), body image and nutrition (63%), violence and personal safety (59%), and sexual health (56%). Finding personally-relevant, high-quality information was a pivotal challenge that has ramifications on the depth and types of information that adolescents can find to answer their health questions. Privacy in accessing information technology was a second key challenge. Participants reported using technologies that clustered into 4 domains along a continuum from highly-interactive to fixed information sources: (1) personal communication: telephone, cell phone, and pager; (2) social communication: e-mail, instant messaging, chat, and bulletin boards; (3) interactive environments: Web sites, search engines, and computers; and (4) unidirectional sources: television, radio, and print. Three emerging roles for health professionals in eHealth include: (1) providing an interface for adolescents with technology and assisting them in finding pertinent information sources; (2) enhancing connection to youths by extending ways and times when practitioners are available; and (3) fostering critical appraisal skills among youths for evaluating the quality of health information.

**Conclusions:** This study helps illuminate adolescent health-information needs, their use of information technologies, and emerging roles for health professionals. The findings can inform the design and more-effective use of eHealth applications for adolescent populations.

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**KEYWORDS**

Adolescent health; adolescent health services; health information; eHealth; information technology; Internet

## Introduction

Health practitioners face several important challenges with adolescents. Adolescence is the developmental stage when health-risk behaviors may be initiated (eg, smoking, drug use, physical inactivity, high-risk sexual behavior, and not wearing protective gear), and when youths move from parental control to establishing their own separate relationships with health professionals [1]. However, youths can be difficult to engage in health care and health promotion, despite having access to more health information than in the past. Studies show that adolescents want to discuss issues with health professionals, but often they do not. For example, Klein and Wilson found in a national (United States) sample of adolescent boys and girls that the majority (70.9%) report at least 1 of 8 potential health risks, but most (63%) had not spoken to their doctor about any of these [2].

On the other hand, adolescents are typically the early adopters of new technologies. The Internet, in particular, provides innovative opportunities for engaging youths, including hard-to-reach populations (eg, youths in rural settings and street-involved youths) and those turned off by traditional health-education approaches. Youths' traditional sources of health information are no longer satisfying their needs, and they are increasingly using the Internet for health-related information [3,4]. A distinct advantage of the Internet is the potential for enhanced outreach in providing eHealth services to the community. Woodruff et al [5] provided initial data regarding the acceptability and impact of an Internet-based chat room for rural teen smokers. Skinner et al [6-8] developed a comprehensive eHealth Web site for youths based on the concept of a virtual island called CyberIsle, which includes an online teen clinic and behavior-change interventions such as smoking prevention and cessation [9].

As health-information sources on the Internet proliferate, concern is being expressed about the quality of this information [10,11] and about difficulties young people have in finding answers to their specific questions [12]. Ho and Lee [13] found a fairly-complicated relationship between computer use and youths' gender and lifestyle. Skinner et al [14] found that the quality of Internet access is not equal and that it greatly influenced young people's ability to obtain health information and resources. Internet-use statistics do not reflect this characteristic. In addition, filtering can restrict access for youths to health information. In a study of pornographic-material filtering, Richardson et al [15] found that at the least-restrictive level software filtered out 87% of erotic Net sites yet blocked 1.4% of health-information sites, and at more-restrictive levels the filtering blocked from 5% to 25% of health-related sites.

Research is illuminating issues about how searches are conducted for information on the Internet. In an observational study of 16 adult subjects, Eysenbach and Kohler [16] found that only 9 participants ever looked beyond the first search pages and 5 of them ever clicked a link on those pages. Hansen et al [17] studied how adolescents search for information using the Internet and found that they typically used a trial-and-error approach and did not consider the source of the content. Using simple search terms on popular search sites for information on smoking cessation for teens, Koo and Skinner [18] found that only 14 of the first 30 retrieved sites were of direct relevance to teen smoking cessation.

The aims of this study were threefold: (1) to identify particular needs that adolescents seek health information about, (2) to analyze how adolescents use various technologies for getting this information, and (3) to examine roles that youths see health professionals playing in linking technology and health information. Based on these findings, a framework is presented for integrating different technologies and information functions in eHealth applications for adolescents.

## Methods

Focus group methodology [19] was used to engage youths in discussions about their health-information and social-support needs, as well as the role that technology plays in addressing these needs. Our aim was to learn about how and why adolescents from diverse cultural, geographic, and socio-economic backgrounds access health information. The open-discussion format allowed youths to share episodes from their lives without prompting.

### Subjects and Site Selection

Twenty-seven focus groups were conducted with 210 youths from across Ontario, Canada; 55% were female and 45% were male. The median age of participants was 16 years (range, 10-28 years). Initial contacts were made with agencies serving youths (health agencies, community centers, drop-in centers, and schools), through a snowball sampling technique that involved obtaining subjects through chain referrals based on an extended network of relationships and contacts across the province. The majority of the focus groups were conducted with preexisting youth groups or in locations where youths congregated for programs. The median age difference within groups was 5.7 years (range, 0-11 years). The few older participants were from the street-involved and Aboriginal focus groups. Consistent with maximum variation sampling [20] in qualitative research, a sampling frame was developed to ensure diversity in terms of age, sex, geographic region of the province, and ethno-racial identity. Stratified sampling using a multistage sampling frame allowed for the inclusion of traditionally underrepresented youths, specifically street-involved youths, youths with physical disabilities, Aboriginal youths, first-generation Canadians, and newly-arrived Canadians. Slightly more than one third of the group sites (10) represented high-risk populations (eg, street-involved). The ethnic representation of the participants was: 28% North, Central, and South American; 22% European; 22% African and Caribbean; 14% pan-Asian; 7% Aboriginal; and 7% not stated. The focus group geographic-location settings were: 3 rural, 3 northern, 4 small urban, and 17 large urban.

### Focus Group Process

The focus groups were, on average, 90 minutes long. To provide consistency, the same TeenNet research associate (SB) who was not known by the participants facilitated all groups. Each focus group site provided a known cofacilitator to enhance participant's comfort, translate the study into terms uniquely understandable to each group, and to help draw out the youths to share their experiences. To reinforce the safety and confidentiality of focus group members, it was agreed that topics discussed in the group would remain confidential unless they impacted an individual's immediate safety. All participants were informed that if immediate safety was a concern the cofacilitator would follow up with the individual. Standard procedures were employed for obtaining informed consent (approved by University of Toronto's Human Subjects Review Committee). Parent or guardian consent was obtained in cases where participants under 18 years of age were not living independently and the focus group site was not a drop-in center.

A warm-up session had each group brainstorm about definitions of health. Initial work showed that unless a broad definition of health was grounded in participants' lives, many of the participants would respond with a narrow focus on health as being either the presence or absence of disease. In the focus groups, youths were asked to share experiences of using information technologies to address: (1) finding health information for self or others, (2) supporting personal change, (3) finding or providing social support, and (4) facilitating collective action. The focus group questions were derived in consultation with 3 committees: (1) selected youths, (2) frontline staff from youth agencies, and (3) a research advisory group. Two pilot groups were conducted to refine question wording and sequence prior to commencing the main study.

### Data Analyses

The audio of all focus-group interactions was tape recorded and transcribed. Several procedures were employed to maximize transcription quality, and to ensure that quality standards were maintained [21]. Verification of the accuracy of the transcriptions was achieved by randomly cross-checking the transcripts against the tapes [22]. Analysis followed a modified grounded-theory approach [23], where a selective coding template was developed based on major data themes [24]. The template was refined and extended following trial application to a cross section of transcripts. The coding template was peer reviewed [25] by the 3 committees and applied to all 27 transcripts using QSR N6 software [26]. Out of the approximately 60 nodes, this article focuses on the 12 technology-related nodes. The 12 nodes were reviewed by a group of 8 researchers for consistency and analyzed for categories, themes, and issues. In weekly analysis meetings, members discussed prepared notes on key themes, issues, and gaps related to a specific technology [27]. Categories, themes, and issues that were common to all the technologies were identified in the final phase of analysis. These were summarized into tables and figures with participant quotes used to illustrate the youths' voices. This analysis identified distinct trends in how youths were using different types of information technologies. As a final step, summary data were presented to a small sampling of cofacilitators for a modified member's check [28].

## Results

### Health-Information Needs

Table 1 summarizes the main issues raised by youths in this study in terms of expressed needs for health information. Table 1 lists the number of groups that raised a particular issue (Coverage) and the amount of time spent discussing a theme (Volume) measured by the number of coded single-line text units. Presenting the data in this format helps portray where health issues fit within the broader realm of adolescent life.

Regarding general health, study participants most-frequently used technology and traditional sources to find information about specific medical conditions and diseases (67%), followed by body image and nutrition (63%), violence and personal safety (59%), and sexual health (56%). The discussion was most extensive around the topic of violence and personal safety (1861 text units). In comparison to physical health, mental health issues were discussed much less often, with suicide and depression (22%) being the most-common examples. Study participants reported having health-information needs related to school (89%); interacting with friends (85%); and finding information about social concerns regarding income, housing, poverty, and employment (85%). Virtually all groups talked about action including personal change. Although study participants discussed mental-health issues less frequently, suicide and depression were an important theme for 22% of the groups.

### Concerns

Study participants raised some key issues about using the Internet to find health information. Quality was discussed as pivotal by all but 1 group (96% of the groups)—having ramifications on the depth and types of information that adolescents can find to answer their health questions. Finding personally-relevant health information was seen to be dependent on Internet-searching skills. Participants reported that they tend to use simple 1-word searches and did not dig deeply into search-engine results pages. Acquiring search skills was seen as dependent on Internet access, including the amount of Internet time available, quality of connectivity (bandwidth), and computer software. A common concern was the ability of the Web resource to answer their specific health related question.

### Linking Technologies With Functions

Study participants reported using various technologies for health information, ranging from traditional formats (television, radio, and printed material) to new venues such as mobile phones and interactive Web sites. Figure 1 provides a graphic synthesis that maps the relevance of the different technologies for meeting the perceived needs of adolescents. The technologies identified by study participants clustered into 4 domains that are differentiated in Figure 1 along a continuum ranging from highly interactive (high level of content customization) to fixed sources (no content customization). Table 2 gives a detailed description of how study participants use the 12 different technologies and the challenges they experience with them.

**Table 2.** Adolescents use of different types of technology

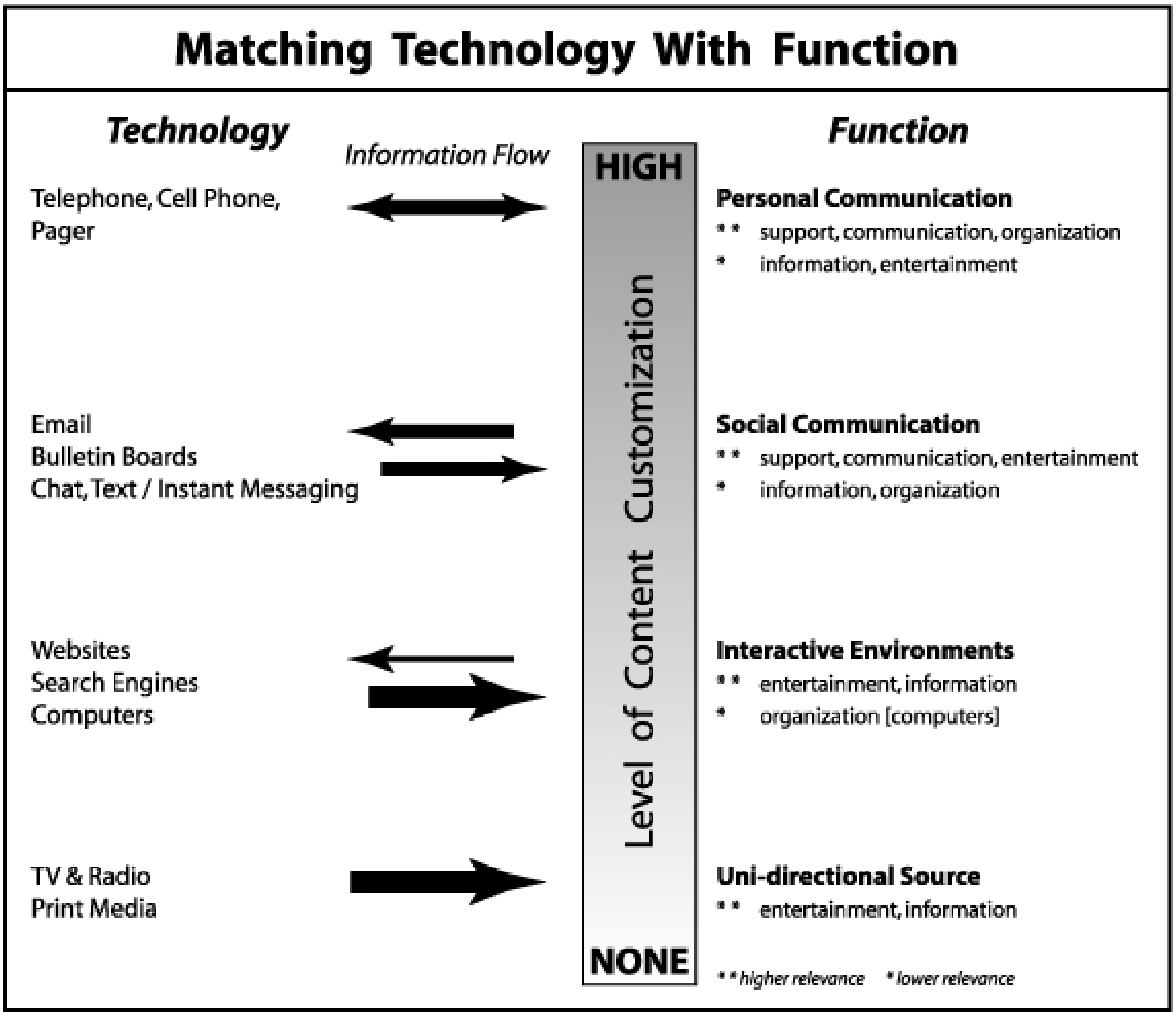
| Technology | Scope Of Use | Challenges |
|---|---|---|
| 1. Personal communication | | |
| Cell phone | • Most often stated purpose was for personal safety<br>• Frequently used to make social plans once adolescents are out of the house | • Big concerns about theft and loss of cell phones<br>• Concern about the privacy of cell phones<br>• Money and debt management<br>• Health impacts of using cell phones |
| Pager | • Safety, privacy, and screening—can choose when they talk to the person<br>• Control of who you talk to—calls coming into adolescents' pagers are only for them | • Fear of losing pager<br>• Pagers are identified with drug dealers and the poor |
| Telephone | • Extensively used for social connection and gossip<br>• Increased credibility for Web sites that offer a contact phone number<br>• Contact professionals for information and appointments<br>• Use 1-800 (ie, toll-free) numbers | • Extra cost for phone services to rural communities<br>• Issues with trust in accepting help lines: statement of confidentiality<br>• Help lines and information lines that use automated menus are frustrating |
| 2. Social communication | | |
| E-mail | • Keeping in touch with people they know<br>• Source of emotional support<br>• Can be easier to write out a personal problem than talk about it<br>• Petitions, subscribing to updates, and newsletters | • Limited access to e-mail<br>• Concern over security of personal identity<br>• Fear of downloading viruses<br>• Unsolicited e-mail: advertising, junk, porn, and stalkers |
| Instant messaging (MSN Messenger and ICQ) | • Keeping in touch with friends and people from school<br>• **Random chats with strangers**<br>• **On-going relationships with ICQ friends**<br>• Cybersex explorations | • Don't know how to use or have access to ICQ<br>• Unsolicited porn and spam<br>• Cost of not having ICQ—being left out of group activities<br>• Fear of censorship and punishment |
| Bulletin board | • Focused discussions, only respond to details shared<br>• Source of referrals and information for specific questions<br>• Mostly spoke with strangers | • Like being anonymous and nonprejudicial<br>• Yet, some youths fear of having identity discovered |
| Chat room | • Play and social interaction<br>• Linking with people with similar experiences and interests<br>• Recovery chat: support dealing with drug and alcohol problems | • Access to chat software is limited<br>• Too much swearing<br>• Too many invitations for cybersex |
| 3. Interactive environments | | |
| Web site | • Internet is first stop for information<br>• Finding information about sensitive issues online<br>• Easy to find information on topics of personal interest eg, grooming, fashion, sports, and music | • Avoiding the social costs of viewing pornography<br>• Access issues limit use at schools<br>• Difficult to find information for personal questions and school-related projects |
| Search engine | • Only 5 or 6 search engines typically used<br>• **Tended to use 1-word searches**<br>• **Only looked at first page of results** | • Either too many or not enough relevant sites identified<br>• Sites without relevant information turning up in the results page<br>• Old data turning up high in results page |
| Computer | • Homework and the organization of information<br>• Computers allows adolescents to be more efficient and effective in school work | • Typing is a barrier<br>• Family income affects quality of technology available to adolescents<br>• Information generated by adolescents is more appealing than adult-only created material |
| 4. Unidirectional | | |

| Technology | Scope Of Use | Challenges |
|---|---|---|
| Radio<br>Television | • Television is a source of credible general information<br>• MP3 use was common<br>• Keeping in touch with local news<br>• Source of music | • Television is passive—can't control what you get<br>• Less current than Web sites |
| Print:<br>• Books<br>• Newspapers<br>• Magazines | • Books are seen as one of the most-credible sources of information for serious projects and health projects<br>• Magazines are good sources of fun and adolescents' culture information (eg, body image, grooming, sports, and music) | • Most paper media depends on literacy<br>• Takes time to find a book and they are usually in a library<br>• Relative speed compared to Web sites; can take too long to read for information |

**Table 1.** Health-information needs raised by adolescents

| Theme | Coverage: Groups that Raised the Issue % (Number) N = 27 | Volume: Number of Coded Single-Line Text Units |
|---|---|---|
| General health | | |
| Medical conditions | 67% (18) | 1252 |
| Body image and nutrition | 63% (17) | 1168 |
| Violence and personal safety | 59% (16) | 1861 |
| Sexual health | 56% (15) | 1174 |
| Drug use and drinking | 44% (12) | 752 |
| Smoking | 41% (11) | 817 |
| Mental health | | |
| Suicide and depression | 22% (6) | 665 |
| Stress | 11% (3) | 79 |
| Grief and loss | 7% (2) | 42 |
| Social | | |
| School | 89% (24) | 4617 |
| Income, housing, poverty, and employment | 85% (23) | 2604 |
| Friends | 85% (23) | 1399 |
| Music and gaming | 78% (21) | 882 |
| Parents and family | 74% (20) | 626 |
| Sports | 63% (17) | 1685 |
| Action | | |
| Collective action (volunteering, activism) | 100% (27) | 8782 |
| Social support | 96% (26) | 9507 |
| Personal change | 96% (26) | 7370 |
| Health-information concerns | | |
| Quality | 96% (26) | 4240 |
| Trust | 67% (18) | 1819 |
| Privacy | 56% (15) | 1104 |

**Figure 1.** Matching technology with functions that meet the perceived health-information needs of adolescents



### *Personal Communication*

Cell phones were most often obtained for personal-safety reasons. Also, they were used to arrange social plans when the youths were away from the home phone. Virtually all types of personal conversations including health issues were considered appropriate when using a cell phone or telephone. The largest barrier with cell phones was cost of the unit, minute plans, and fear of debt; for example, ". . . so you're not building up a debt when you're only like sixteen years old." Mention of pagers was less common in the discussions, due to their negative association with the drug culture. A perceived strength common to pagers and cell phones was privacy. Telephones were almost invisible in the group discussions—some groups did not even consider them technology. The availability of toll-free numbers for health information was important to all youths. However, a major barrier to the use of toll-free support numbers was voiced by rural and northern youths, who were concerned that they were not eligible because of geographic isolation (a misperception). Geography also affected the availability of cell phone and pager service.

### *Social Communication*

Study participants considered e-mail the most-accessible technology. It was used for everything from short messages and receiving health bulletins to providing and receiving emotional support. According to one youth: "like if you want to tell them something and you don't want to tell them over the phone or in person because it's kinda . . . hard to say." Finding and keeping an e-mail address was viewed by youths as very important. The largest barrier was related to timely and private access. Instant messaging (MSN Messenger and ICQ) was used mainly for social conversation with friends and "chat friends" formed in the virtual world—not as a venue for sharing feelings and personal disclosures about health-related concerns. However, access to instantaneous chat was not as common as e-mail. Bulletin boards were seen as a valuable source of health information because the anonymity provided an unbiased place to share personal information about health concerns; for example, ". . . read them all over and see which one is good." It also allowed participants to share expertise by providing advice without risking personal safety. Then again, some participants raised concerns about privacy and their ability to maintain anonymity in face of other's superior technological skill. Another concern was that information obtained from bulletin boards is of questionable quality. Chat rooms supported personal disclosure and participation in specialized topics ranging from sports and music to addictions; for example, "if you want advice, there's like advice chat room(s)." Group members were concerned about the amount of offensive content such as unsolicited sexual advances.

### *Interactive Environments*

When using technology, Web sites were the first place that study participants looked for health information. However, important concerns about using Web sites were the consistency and quality of information. School-related information was perceived to be much more difficult to find on the Web than entertainment or social information. Unless a specific URL had been recommended to youths, they typically used their favorite search engine to find Web sites. However, search engines were often experienced as frustrating because of their tendency to uncover too few relevant or too many extraneous sites. One participant commented: "too many things to choose from. If you're looking for one site, at least twenty-five are gonna pop up that are completely different."

Participants found computers to be pivotal in their ability to perform work. Indeed, participants in our study strongly believed that not having a computer or possessing a slow system leaves youths with diminished ability to develop necessary computer skills and to perform in school. This point was underscored by the comment of one participant: ". . . if you don't have enough money to buy a computer you can't really use that stuff right?" Geographic issues impacted on using these technologies for health information. In particular, the limited availability of Internet service or broadband connectivity affected youths in relatively-small urban, rural, and northern communities.

### *Unidirectional Sources*

Radio and television were mostly used for relaxation and entertainment because of the lack of control over content. According to one participant: "TV you can't ask a question." However, The Learning Channel was cited as a source of health information. Books were commonly used to verify information obtained from Web sites but only in cases involving a serious health issue or an important school assignment. Youths in this study tended to have greater trust about books as an information source; for example, ". . . they won't publish a book that has inaccurate information." Magazines were seen as easily-obtained credible sources of information. Magazines were described like Web sites: short, graphical, easy to digest, and immediately relevant. The largest barrier to using books and newspapers was literacy level.

### *Technology Functions*

According to the thematic analyses, adolescents use the various technologies to serve 5 major functions (see Figure 1):

1. Entertainment: finding information about personal interests (eg, movies and sports), having fun in chat rooms, and playing virtual games
2. Information: gathering and sharing information for personal use and school work
3. Communication: interacting with friends and strangers
4. Organization: collaborating on projects and organizing people/events
5. Support: connecting with others to give or receive self support and mutual support.

Entertainment was the most frequent reason study participants used technologies. In addition, they used information technologies to answer health questions, become better informed, and share the resulting information with others. The availability of safe, appropriate opportunities to connect with others and create virtual support networks was highly valued. This connection was seen to provide a nonthreatening environment for discussing sensitive personal health concerns (eg, sexual activities). Although getting help and support with personal issues was mentioned least often by participants, strong opinions were voiced about the appropriateness of using social communication technologies in this way (eg, concerns about maintaining anonymity).

## Technology and Emerging Roles for Health Professionals

A higher-order analysis of the data focused on studying youths' perspectives about technology and the role of health professionals in their lives. Three emerging roles were identified (Table 3).

First, practitioners and health care settings can provide a major interface with eHealth technology and applications. Youths looked to practitioners for assistance in finding and evaluating information about a particular health need. For example, "go to your doctors and ask them if they . . . can point you where to go."

Second, eHealth technology can enhance interactions and personal connection of adolescents with health practitioners. One study participant described a situation where "instead of going to the doctor I went on the Internet . . . afterwards I went to the doctor because I didn't think the Internet helped me that much." Technology can extend the ways and times when practitioners are available—enabling them to be more approachable for adolescents around their health concerns.

Third, health practitioners can play a major role helping youths build critical appraisal skills for evaluating the quality of health information found through eHealth sources. This need was stated by one youth: "go to the Internet for quick information . . . but knowing that it shouldn't be trusted."

**Table 3.** Emerging roles for practitioners and health care settings in eHealth

1. Providing a technology interface and direction:
   - Provide a key interface for adolescents with eHealth resources
   - Assist and augment adolescents in their access to quality health information
   - Serve as an important backup resource to eHealth information
   - Provide direction on where to get further information and assistance

2. Enhancing connection and trust:
   - eHealth provides practitioners with an entry to build relationships and trust with their young patients
   - eHealth enables practitioners to be more engaging with adolescents and increase their readiness to look at personal health issues
   - Technology can extend times when and venues where practitioners are available

3. Fostering critical appraisal:
   - Help adolescents develop skills for assessing the quality of health information
   - Encourage critical perspectives about health information and eHealth sources
   - Encourage and help adolescents develop digital-literacy skills

## Discussion

Searching for health information using eHealth technology can seem to adolescent health consumers like running in a maze. A key concern identified in this study was being overwhelmed by information, yet not being able to get a specific question answered. This frustration was expressed quite succinctly by one youth: "it can get just overwhelming on just the number of sites that have nothing really to do with what you're looking for." Adolescents frequently make health-related decisions in isolation from traditional health sources. However, study participants reported that they find this task difficult and want better support.

Internet technologies could be used to augment gaps when traditional venues for health information are less available (eg, professionals) or perceived to be less helpful (eg, pamphlets). Many adolescents prefer using information technology to traditional sources in situations that may cause embarrassment with peers or conflict with parents or teachers. Bulletin boards and specialized chat rooms are popular places to pose questions and gather information. Adolescents indicated that their peers (online and off) are primary sources of health information. However, this raises concern because of the "personal" nature of information shared. Adolescents indicated they turn to Internet-based health resources because of its 24-hours-per-day availability, and its lack of perceived judgment and conflict. Yet, there was considerable debate among study participants about the appropriateness of this venue for sharing personal health information.

Study youths indicated that they would be open to increased interaction and support from health practitioners. They saw practitioners as reliable experts on health information, but noted barriers to having timely access to them. They were aware that health practitioners have an expertise in both assessing and finding quality health information. This was seen as very important because participants acknowledged gaps in their skills (eg, sorting through "too many" information sources from a search engine request), especially when looking for specialized and personal health information. They were receptive to health professionals using their expertise to help them bridge the gap between information they are currently finding and the potentially higher-quality health information available on the Internet. For example, practitioners could help by: recommending Web sites for specific health issues, giving advice about topic search strategies, and providing guidance on critical appraisal of information found.

Whereas one of the biggest draws of the Internet is that it is potentially available at all times (24 hours per day, 7 days per week), a major limitation described by study participants was access to health professionals—eg, they are only available by appointment. For adolescents living in small communities another barrier was privacy. According to one participant: "You can't even trust a doctor or anyone in a small town - they are professional but they also live here." The nature of small towns raises concerns about health professionals inadvertently linking requests for sensitive information back to adolescents' social networks (especially parents). This vulnerability left some youths hesitant to approach practitioners about potentially-embarrassing topics.

New and expanding roles are emerging for health professionals to integrate eHealth resources into their clinical practice and community outreach. The map (Figure 1) summarizes how study participants used the various information technologies in performing 5 common functions. It underscores a key point for practitioners and developers of eHealth applications—"health" is not a primary concern of most youths. One needs to go where they are (entertainment, communication, and organization functions) as a stepping-stone to health issues (information and support functions). The map can help practitioners understand how their young patients use technologies in their daily lives. Also, the map can help guide eHealth program development in matching appropriate technologies to health-information needs of adolescent populations.

In conclusion, this study underscores the many challenges adolescents face in getting quality health information using technology. The findings provide a better understanding about the health-information needs and concerns of youths, and the ways that they use various technologies. At the same time, the study helps illuminate some enhanced and innovative roles for practitioners and health care settings in better serving the needs of adolescents via eHealth.

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## Conflicts of Interest

None declared.

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Review

# Generic Design of Web-Based Clinical Databases

Jacob Anhøj, MD, DIT

**Corresponding Author:**
Jacob Anhøj, MD, DIT
AstraZeneca A/S
Business Communication
Roskildevej 22
DK-2620 Albertslund
Denmark
Phone: +45 43666275
Fax: +45 43666100
Email: jacob@anhoej.net

## *Abstract*

**Background:** The complexity and the rapid evolution and expansion of the domain of clinical information make development and maintenance of clinical databases difficult. Whenever new data types are introduced or existing types are modified in a conventional relational database system, the physical design of the database must be changed accordingly. For this reason, it is desirable that a clinical database be flexible and allow for modifications and for addition of new types of data without having to change the physical database schema. The ideal clinical database would therefore implement a highly-detailed logical database schema in a completely-generic physical schema that stores the wide variety of clinical data in a small and constant number of tables.

**Objective:** The objective was to review the medical literature regarding generic design of clinical databases.

**Methods:** A search strategy was devised for PubMed and Google to get the best match of peer-reviewed articles and free Web resources on the subject.

**Results:** Eight peer reviewed articles and a Web tutorial were found. All the resources described the so-called Entity-Attribute-Value (EAV) design as a means of simplifying the physical layout of data tables in a clinical database. In Entity-Attribute-Value design all data can be stored in a single generic table with conceptually 3 columns: 1 for entity (eg, patient identification), 1 for attribute (eg, name), and 1 for value (eg, "Jens Hansen"). To add more descriptive fields to the entity class, all that is necessary is to add attribute values to be stored in the attribute field. The main advantages of the Entity-Attribute-Value design are flexibility and effective entity-centered data retrieval. The main disadvantages are complicated front-end programming needed to display data in a conventional layout that the user understands and less-efficient attribute-centered queries. The Internet offers unique opportunities for database deployment, eliminating problems of user-interface deployment. Furthermore, Web forms may be generated in a completely-generic fashion during run time from metadata describing the semantic structure of clinical information stored in the database.

**Conclusions:** The Entity-Attribute-Value model is useful for generic design of clinical databases. Depending on the specific requirements of the application, more or less complex metadata models may be applied.

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**KEYWORDS**

Databases; medical informatics applications; software design; Internet

## *Introduction*

Clinical databases may contain a large variety of data from different domains, eg, patient visits, test results, laboratory reports, diagnoses, therapy, medication, and procedures. Clinical databases may have different purposes, eg, patient management, electronic patient records, clinical research, and quality control. Clinical databases usually have a large number of users with different requirements for views of the database. The administrator does not want to view data per patient, while the nurse must be able to lookup current medication for a specific patient. The researcher may want to do data mining on clinical information for thousands or millions of patients, and the clinician should be able to see his or her ambulatory schedule. Most clinical databases comprise only a part of these functionalities, but these examples illustrate the challenge that designers of clinical databases face. Furthermore, in contrast to schemas from many other domains (eg, finance and public administration) the logical data schemas of clinical data are always incomplete and developing.

In databases, an entity is a single person, place, or thing (eg, patient or diagnostic test) about which data can be stored. In conventional relational database design, each entity is mapped to one or more tables using values of one or more rows to uniquely identify each record. That means that for each entity there exists at least one table. This strategy works well for most databases even if the number of concepts involved in a domain may be high. As long as the domain of interest remains relatively unchanged, the table layout (ie, the physical schema) should work well for many years. The domain of clinical science in particular (and biology in general) is, however, under constant development as new concepts appear and old concepts are modified or deferred.

In a conventional database (that is, in a conventional relational database), new tables must be created to record new concepts. To give users access to the new tables, new forms must be designed and links to these forms must be provided in the user interface. If a table that is already in the database needs to be modified care must be taken not to destroy existing data and not to break any constraints. Accordingly, user-interface forms must be redesigned to reflect changes (eg, fields that have been added or removed) in existing tables.

The complexity and the rapid evolution and expansion of the domain of clinical information thus require a large maintenance overhead if data are laid out using a conventional design. For this reason, it is desirable that a clinical database be flexible and allow for modifications and for addition of new types of data without having to change the physical database schema. The ideal clinical database would therefore implement a highly-detailed logical database schema in a completely-generic physical schema that stores the wide variety of clinical data in a small (and constant) number of tables.

The aim of this project was to provide an overview of techniques and problems in generic design of Web-based clinical databases.

## Methods

Medline was searched through PubMed [1]. Searching was done by trial-and-error using combinations of keywords to get the best match of articles covering the problem. Furthermore a search strategy was devised for Google [2] using a similar trial-and-error strategy.

## Results

The final PubMed search was done on July 11, 2003 using the search term:

```
(generic database design clinical) OR (entity
attribute value).
```

This term was translated by PubMed into:

```
(((entity[All Fields] AND attribute[All Fields])
AND value[All Fields]) OR (((generic[All Fields]
AND
("databases"[MeSH Terms] OR database[Text Word]))
  AND  design[All  Fields])  AND  clinical[All
Fields])).
```

Thirty-three papers were found and 13 were selected based on their title. Of these, 7 were selected based on their abstract and the full-text papers [3- 9] were either downloaded or ordered from the Danish National Library of Science and Medicine.

Google was searched on the same day using the search term:

```
clinical database generic design.
```

The search was restricted to the first 30 hits. One additional paper [10] and 1 Web resource [11] of interest were found.

The 9 resources were all from either of 2 research groups: Department of Medical Informatics, Columbia University, New York, NY and Center for Medical Informatics, Yale University, New Haven, Conn. Three production databases were the basis of the 2 group's research: The Clinical Data Repository at Columbia-Presbyterian Medical Center (CPMC), the Adaptable Clinical Trials DataBase (ACT/DB), and SENSELAB.

CPMC [8- 10] is a large clinical repository for millions of patients dating back to the beginning of the nineteen nineties. Several front-end applications offer access to the database giving different views for health care professionals, administrators and researchers.

ACT/DB [3,4,6,7,11] is a clinical-trials database built upon the same design principles as CPMC. Nadkarni et al introduce the term "entity-attribute-value (EAV) design" for generic structuring of data in a relational database [7]. The database is accessible through a generic Web-based interface (WebEAV) [4]. Web forms for displaying and editing data are generated automatically during run time from metadata stored in the database.

SENSELAB [5] is a database for heterogeneous neuronal data. As such it is not a clinical database. However, the SENSELAB architecture uses an object-oriented approach to the EAV model by defining classes and relations (EAV/CR). The EAV/CR architecture is useful for scientific data in general, but it is of special interest for clinical databases.

The principles and design issues involved in these databases are the focus of the remainder of this paper. I will not go into details about the specific implementations of these systems, rather I will present techniques involved in the design of generic database systems. For design details about the 3 database systems the reader is encouraged to consult the references.

### Entity-Attribute-Value Design

In conventional database design, each parameter of interest is represented in a separate column in a table. As new kinds of data need to be managed, the number of columns and/or tables needs to grow.

To add a new attribute for patient description (eg, phone number) to a conventional relational database design (Table 1), another column has to be added to the table.

**Table 1.** Conventional relational database design (example)

| PatientID | Name | Date of Birth |
|---|---|---|
| 1 | Jens Hansen | 1956-Aug-01 |
| 2 | Hans Jensen | 1974-Sept-04 |

In EAV design, however, data may be stored in a single table with (conceptually) 3 columns: 1 column for entity identification, 1 for attribute, and 1 for the value of the attribute (Table 2).

**Table 2.** EAV (Entity-Attribute-Value) database design

| PatientID | Attribute | Value |
|---|---|---|
| 1 | Name | Jens Hansen |
| 1 | DateOfBirth | 1956-Aug-01 |
| 2 | Name | Hans Jensen |
| 2 | DateOfBirth | 1974-Sept-04 |

To add a phone number attribute in the EAV table (Table 2), all that is required is to define a new code for phone number to be stored in the attribute column. No change to the table schema is needed. Theoretically, most of the facts that are stored in a database can be stored in a single EAV table.

The EAV design has several advantages:

- **Flexibility:** There are no limits to the number of attributes per entity. The logical database schema can grow without affecting the physical schema.
- **Storage:** In a clinical database thousands of parameters are available while only a few may be recorded for each patient. In a conventional design this may lead to empty (NULL) fields. The EAV design does not need to reserve space for attributes with NULL values.
- **Efficient entity-centered queries:** If, for example, all information for a single patient is needed, it is necessary to query all data tables looking for information about this patient. In a conventional database this may be a time-consuming task that requires looking through hundreds of tables each of which may or may not have information for this patient. As the number of tables and columns grow, the query must be reprogrammed. In an EAV database only 1 table needs to be queried, no joins are necessary, and no change of code is required as the domain evolves. (A join combines data from 2 or more tables based upon a common attribute.)

The EAV design has, however, some drawbacks:

- **Data display:** As discussed later, the user naturally regards data as being organized conventionally in tables and columns regardless of the physical layout of data. Consequently it may be necessary to transform ("pivot") EAV data into a conventional layout when displaying data. This and other tasks that a conventional database would do automatically (eg, referential integrity checking or form-to-subform linkage) require considerable front-end programming in EAV designs. (Referential integrity checking is checking that values in one table that are intended to be used as keys to another table are indeed found in the second table.)
- **Less-efficient attribute-centered queries:** In contrast to entity-centered queries, complex attribute-centered queries, which are based on attribute values, are significantly less efficient and technically more difficult in an EAV database than in a conventional database. The query "show me all patients whose name starts with *J* and whose date of birth is earlier than 1970" is straightforward in a conventional database. To achieve the same result in an EAV database, set operations (for example, INTERSECT) or joins on multiple versions of the EAV table would have to be performed. (INTERSECT is an operation that compares 2 queries to identify records that are found in both.) Set operations and joins are considerably slower than simple select operations. As the number of attributes increase the execution time increases exponentially. Querying EAV data will be discussed in greater detail later.
- **Constraint checking:** In a well-designed conventional database, constraint checking is either unnecessary or trivial. For example, in a conventional table non-null constraints may be placed on columns to prevent incomplete records from being saved. An incomplete record would appear if, for example, the user forgets to fill in a field on a form. In an EAV table a missing attribute-value pair would normally result in a missing record. For example, if no record for one patient's last name is saved in the EAV table this will—from a logical point of view—lead to data that is inconsistent, in the sense that the data for this patient will not be similar to the data for other patients. To prevent this from happening in an EAV database, checking of such constraints should be programmed into the user interface.

## Metadata

EAV design is a way of simplifying the physical schema of the database, making it domain-independent. Regardless of the physical schema, the user naturally perceives the data as conventionally structured in tables and columns. The *logical schema* of the database reflects the user's perception of the data. In an EAV database the logical schema differs greatly from the physical schema. In a conventional database the two are similar. Therefore, an EAV system must have some means of translating the physical schema into a logical schema that reflects the user's understanding of data. This is achieved through metadata (or dictionary) tables whose content defines the semantics of the domain being modeled. An example of a metadata table could be a table listing the attributes available to the data in Table 2. In this example the metadata table would have 2 records, Name and DateOfBirth. If it is necessary to record further information about patients, eg, sex and phone number, that information should simply be added to the metadata table. Thus, in this case, metadata represent what would be the column names of a conventional data table. The metadata model may be enhanced considerably by, eg, adding more descriptive attributes to the metadata table. These attributes may have several purposes—eg, definition of an attribute's data type, constraints, or display layout (text field, select box, etc). These issues will be discussed in greater detail in the next section.

## Evolution of the EAV Model

In the following sections, I give examples of different EAV schemas going from the most-simple, least-flexible to the most-advanced, most-flexible schema. The term "simple" is not to be interpreted as inadequate. The simple solution may be the right solution for a specific task.

The examples reflect the systems described in the literature but are simplified for pedagogical reasons.

### *A Simple EAV Model*

A simple EAV schema for a clinical database is outlined in Figure 1.

**Figure 1.** Simple EAV schema for a clinical database. (The crows-foot symbol—3 small lines at the end of a relationship line—illustrates a one-to-many relationship between patient and data, and between attribute and data. Text in each ellipse identifies table type.)

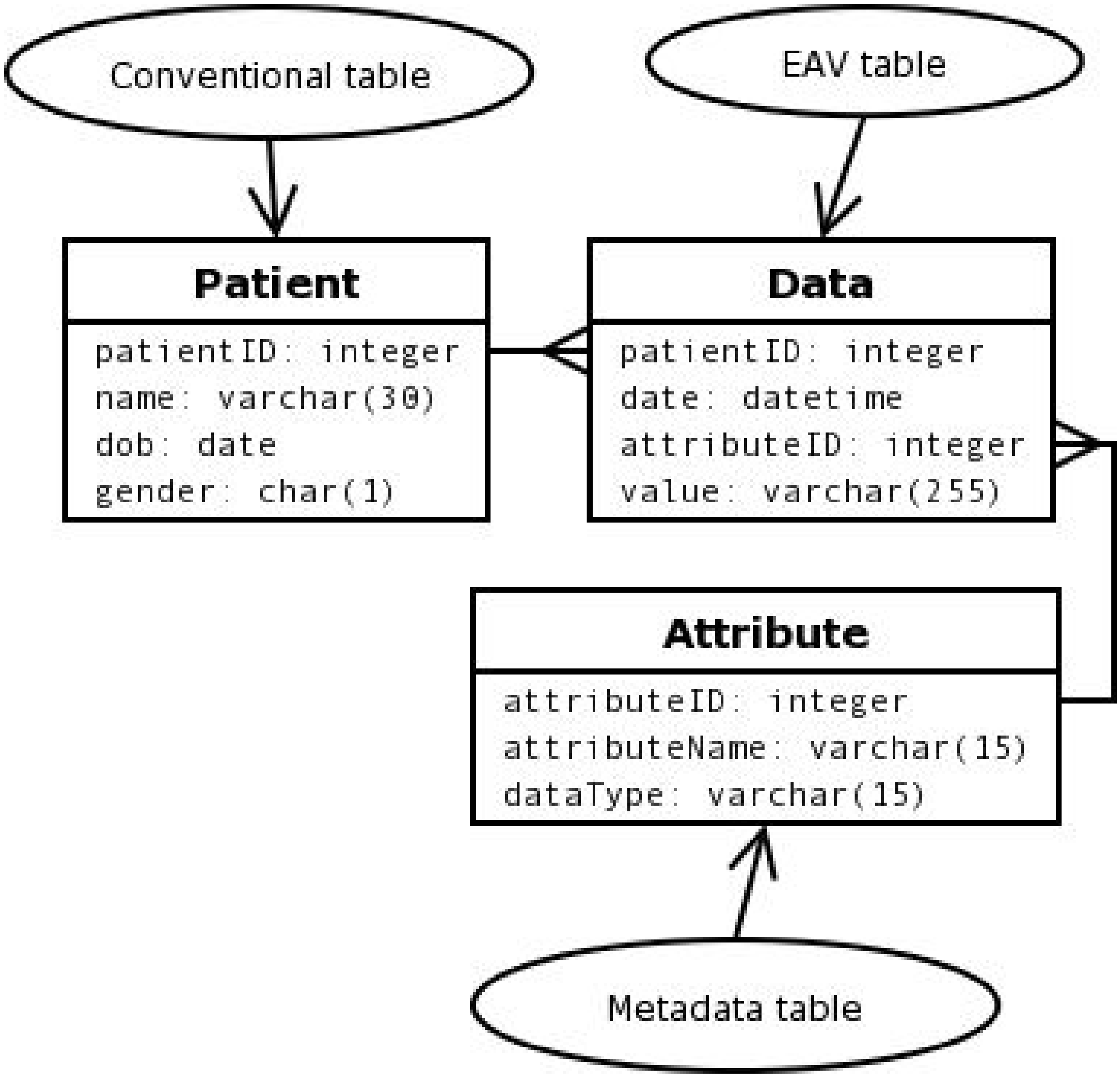


Table 3 shows the database tables depicted in the schema of Figure 1. Data have been arranged in a conventional table for patient demographics, an EAV table for clinical events, and a metadata table defining the attributes available to the EAV table.

Table 3 represents the patient from Table 1 after a course of influenza that started July 1, 2003 and ended July 11, 2003:

The entity part of the Data table is defined by the combination of patientID and date. The attributeID column holds a reference to the Attribute table, which defines the name and type of available attributes. In a real-world production database there would probably be another table to hold the definition of data types.

Values may of course be of any type, for example, text, number, or Boolean (true/false). In the example in Table 3, the Value field of the Data table is text type. Such a design achieves simplicity by storing all simple types as text values. This approach has, however, some drawbacks. First, not all data types will fit into a text field. Binary objects, eg, x-ray pictures or ECG (electrocardiogram) curves, are too large as are long texts (memo-fields). Second, queries based on values will be less efficient for nontextual values. The text "12" is less than the text "2" even though it is numerically greater, because text is sorted character by character, from left to right.

**Table 3.** Database tables for the simple EAV schema in Figure 1

| | | | |
|---|---|---|---|
| **Patient table**[*] | | | |
| patientID | name | Date of Birth | gender |
| 1 | Jens Hansen | 1956-08-01 | Male |
| **Data table** [†] | | | |
| patientID | date | attributeID | Value |
| 1 | 2003-07-01 | 1 | Influenza |
| 1 | 2003-07-01 | 2 | 2003-07-11 |
| **Attribute table** [‡] | | | |
| attributeID | attributeName | dataType | |
| 1 | Diagnosis | Text | |
| 2 | EndDate | Date | |

[*] Conventional table for patient demographics.

[†] EAV table for clinical events (data).

[‡] Metadata table defining attributes available to the EAV table.

Different strategies have been used to store binary data and to increase the efficiency of value-based queries. The simple solution is to ignore the problem and accept that all values be stored as text. This approach may be fully acceptable if it is not necessary to store binary data and if fast value-based queries of large data sets are not required. Another approach is to add a column to the Data table for each data type necessary. For each record, only 1 value-field will be filled in (Table 4).

**Table 4.** Data table with a column for each data type, as a strategy for storing binary objects

| patientID | date | attributeID | textValue | numericValue | longValue | dateValue |
|---|---|---|---|---|---|---|
| 1 | 2003-07-01 | 1 | Influenza | | | |
| 1 | 2003-07-01 | 2 | | | | 2003-07-11 |

This approach, of course, does not comply with rules for good database design as empty fields are recorded for each record. It may, however, be acceptable in small "quick-and-dirty" applications [12].

The most solid and, from a database designer's perspective, correct solution is to segregate the data table into a number of tables based on the data type of the attribute (Table 5).

**Table 5.** Data table segregated into multiple tables based on the data type of the attribute, as a strategy for storing binary objects

| **Data table** | | |
|---|---|---|
| patientID | date | dataID |
| 1 | 2003-07-01 | 1 |
| 1 | 2003-07-01 | 2 |
| **DataDate table** | | |
| **dataID** | **attributeID** | **value** |
| 1 | 2 | 2003-07-11 |
| **DataText table** | | |
| dataID | attributeID | value |
| 2 | 1 | Influenza |

This approach is used in CPMC, ACT/DB, and SENSELAB. For simplicity I chose to show only 1 data table in the illustrations.

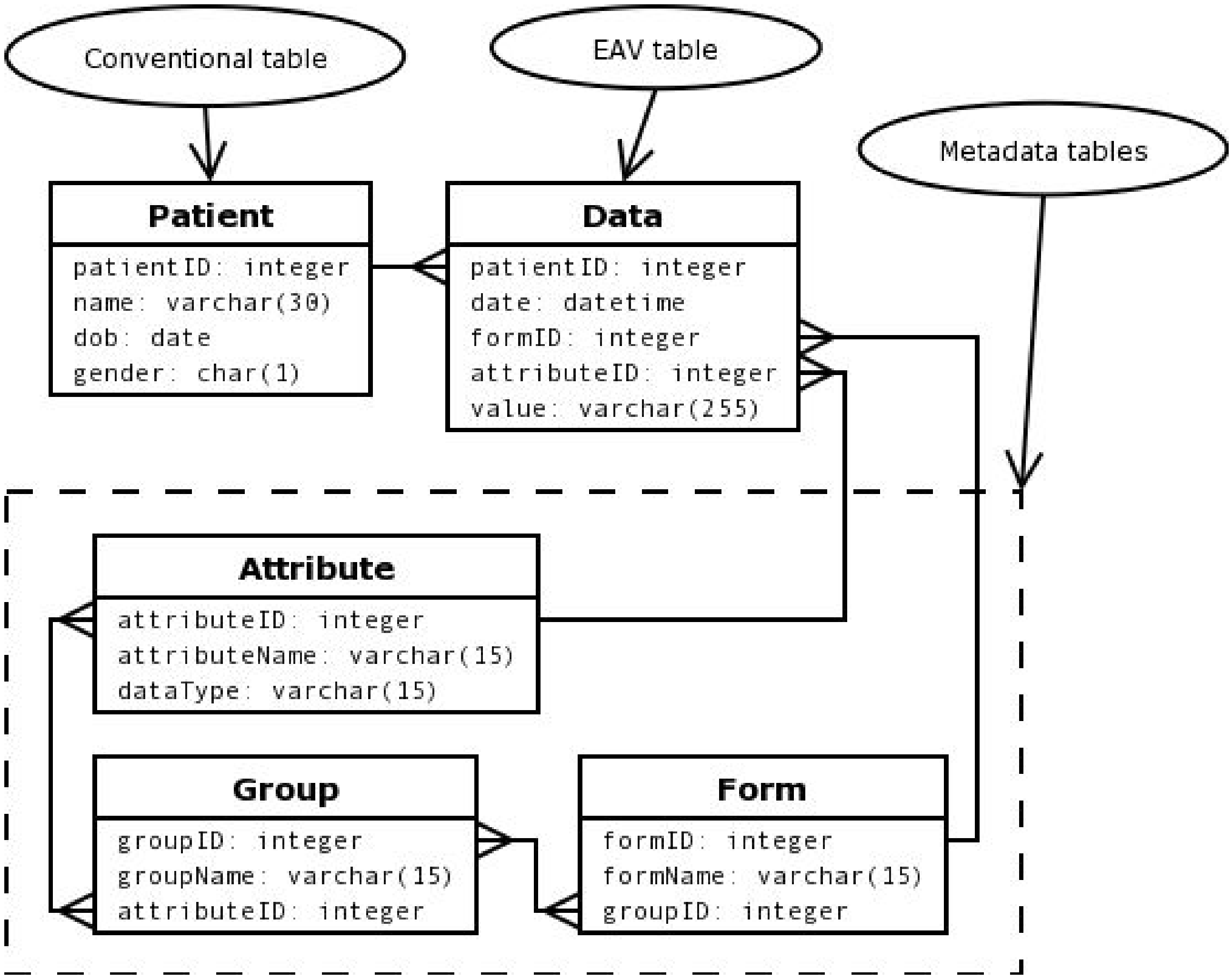
The modeling of patient demographic data in a separate conventional table rather than in the EAV table is deliberate (although not necessary). For a schema that is not expected to change often, as is the case with patient demographics, the advantages of an EAV layout do not exceed its disadvantages; and conventional tables and EAV tables can coexist happily together. Furthermore, this design makes it easy to model the one-to-many relation between patient and clinical events. Relations between entities in an EAV table are complicated to model in the simple EAV design. In an electronic patient-record system, for example, it should be possible to record relationships between clinical events (eg, infection leads to a course of penicillin or myocardial infarction leads to death). The enhancement of the EAV design to handle complex relationships between classes will be described later with the EAV/CR schema.

For a simple application intended mainly for data entry, the simple EAV schema may suffice. With the need for a more-advanced user interface for data-display and input purposes, however, some means of grouping attributes becomes necessary. With the simple EAV schema, grouping attributes together on display forms may be done only by entity (patientID and date) or attribute. The application has no way of telling how EAV data records are related and should be displayed together—eg, multiple values from the same blood chemistry panel.

## Enhancing the EAV Model

Grouping related attributes for display purposes may be accomplished in several ways. One or more descriptive columns may be added to the "entity part" of the Data table, or the metadata schema may be enhanced. An example of a combination of both methods is shown in Figure 2.

**Figure 2.** Enhanced EAV schema with grouping of attributes for form display. (Text in each ellipse identifies table type.)



A group table and a form table have been added to the metadata schema. Attributes may now be grouped and attribute groups may be part of forms. To the entity part of the Data table a new field, formID, has been added telling the application to which form a data record belongs. Now any medical event recorded in the Data table belongs to a form and then may be displayed together with all the other attributes on that form. Furthermore, this design facilitates reuse of attribute groups on different forms.

Depending on the domain being modeled and the requirements of the users, other metadata schemas may be suitable.

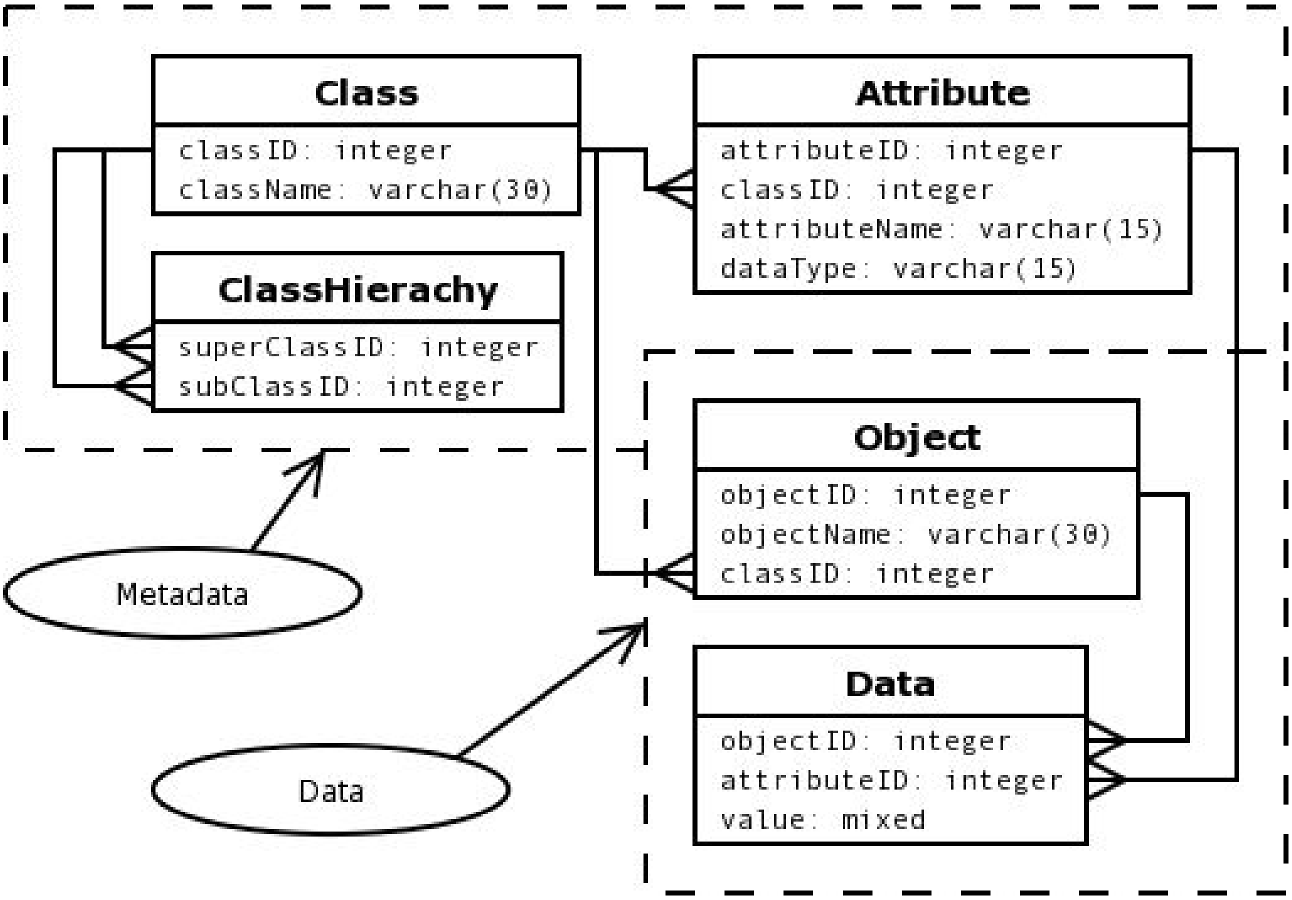
The simple and the enhanced EAV schemas discussed above are examples of the use of generic EAV tables in clinical database applications. Although to some degree generic, the proposed schemas will need adjustment to the actual domain in question. To achieve total domain-independence more refined models must be created.

### *An Object-oriented Approach to EAV Modeling*

The EAV/CR model adds an object-oriented framework to the EAV model by definition of classes and relations. The EAV/CR model was developed for scientific data in general but is useful for clinical data [5].

Figure 3 shows a simplified example of the EAV/CR table layout used in the SENSELAB database. The class and the attribute tables hold the definitions of classes and their fields. The ClassHierachy table records relations between classes. In this example a subclass can have any number of superclasses, and a superclass can have any number of subclasses. The attribute table records the class to which the attribute belongs and the type of attribute. An attribute can be of any simple type and may even be of class type. Class instances (objects) are recorded in the Object table and instance fields are recorded in the Data table, which is similar to the data table in the simple EAV models.

**Figure 3.** EAV schema with classes and relations (EAV/CR). Simplified from Nadkarni et al [5]. (Text in each ellipse identifies table type.)



The example in Table 6 depicts 2 classes, patient and doctor, which are subtypes of a common person class. The patient class has an attribute of object type referring to the patient's responsible doctor. For readability IDs are presented as names instead of numbers.

This example illustrates the use of *inheritance* and *composition* in database design. Inheritance and composition are two important concepts in object-oriented programming. Inheritance can be regarded as an "is-a" relationship between objects—a patient *is a* person, and a doctor *is a* person. Composition is often referred to as a "has-a" relationship—a patient *has a* doctor.

Thus, with this simple layout with (conceptually) just 5 tables, any real-world object can be recorded. Furthermore, objects may be part of other objects; and objects may be related through inheritance. Ad hoc relations between objects (eg, penicillin leads to rash) may be recorded as objects themselves. For this purpose, a class, ObjectRelation, could be defined with 2 attributes, objectID and relatedObjectID. More descriptive attributes may be added to this class if required—eg, causality.

Obviously, considerable up-front programming is required to drive an ergonomic user interface for the EAV/CR model in a real-life production environment. On the other hand, this is a one-time-only job. Another drawback of the EAV/CR design is that the system administrator must have a solid understanding of the object-oriented framework in order to design useful classes. An EAV/CR database is therefore hardly an end-user tool for the average clinician or researcher. As always, flexibility comes with a price.

**Table 6.** Database tables as an example of the EAV schema with classes and relations (EAV/CR) in Figure 3

| | | |
|---|---|---|
| **Class table** | | |
| className | | |
| Person | | |
| Patient | | |
| Doctor | | |
| **ClassHierachy table** | | |
| superClassID | subClassID | |
| Person | Patient | |
| Person | Doctor | |
| **Attribute table** | | |
| classID | attributeName | dataType |
| Person | Name | Text |
| Person | Date-of-birth | Date |
| Patient | Doctor | Class: Doctor |
| Patient | Gender | Text |
| Doctor | Position | Text |
| **Object table** | | |
| objectName | classID | |
| Patient01 | Patient | |
| Doctor01 | Doctor | |
| **Data table** | | |
| objectID | attributeID | value |
| Patient01 | Name | Jens Hansen |
| Patient01 | Date-of-birth | 1956-08-01 |
| Patient01 | Doctor | Doctor01 |
| Patient01 | Gender | Male |
| Doctor01 | Name | Doc |
| Doctor01 | Date-of-birth | 1960-03-12 |
| Doctor01 | Position | Head |

### *Querying EAV Data*

From a database perspective, querying EAV data is not different from querying conventional data. As mentioned earlier, however, in an EAV database, the physical layout differs greatly from the logical layout, and the user generally wants to see data displayed in a conventional format.

As an example, querying Table 1 for facts about patients whose names start with *Jens* and who were born before 1970 is straightforward:

```
SELECT *
FROM table1
WHERE name LIKE 'Jens%'
  AND dob < '1970';
```

To achieve the same result from querying Table 2 requires executing a rather-complex SQL (Structured Query Language) statement:

```
SELECT d1.patientID AS patientID,
       d1.value AS name,
       d2.value AS dob
FROM table2 AS d1 INNER JOIN table2 AS d2
  USING (patientID)
WHERE d1.attribute='name'
  AND d1.value LIKE 'Jens%'
  AND d2.attribute = 'dob'
  AND d2.value < '1970';
```

The same result may be obtained in several ways, but in any case the query must include set operations (INTERSECT) or as in this example a self join for each attribute. (A self join is a join of a table with itself.) Aside from being complex and out of reach for most end users, these operations are far slower than simple select statements.

I did an experiment using data for one million patients described by 3 attributes: name, date of birth, and gender. These facts were duplicated in a conventional table and in an EAV table in a MySQL database. Three queries were performed on each table with 1, 2, and 3 attributes respectively. Execution time was approximately 2 seconds for the conventional table irrespective of the number of attributes. For the EAV table execution time was 7, 14, and 24 seconds respectively. Thus execution time increases linearly with the number of rows (1 million in the conventional table and 3 million in the EAV table) and—in the EAV table—with the number of joins involved in a query. In the conventional table, however, the number of joins did not affect query time.

Some strategies have been suggested to deal with this problem:

- There may not be a problem. Attribute-centered queries are important for research questions; their performance is not critical for the care of individual patients. If the need for cross-patient data is infrequent the advantages of EAV design probably exceeds the disadvantages.
- Any need for regular cross-patient data access could be met by making backups of the production database and restoring them onto separate hardware. Resource-intensive queries run on the backup data will not affect the production server. Additionally, the EAV data schema could be transformed into numerous conventional tables after backup thus easing query design by end users with modest SQL skills [6].
- If complex, attribute-centered, user-defined, ad hoc queries are important to an application, steps should be taken to facilitate this. First, a user interface, whether graphical or not, should be built to help users retrieve data. The user should be able to freely select any combination of attributes and criteria. The interface should then translate user requests into semantically-valid and syntactically-valid SQL statements; and from the user's point of view, it should not matter whether data are stored in conventional tables or EAV tables. This approach was taken by Nadkarni and Brandt in the development of the ACT/DB Query Kernel [6].
- Optimization of queries may increase the efficiency considerably. Breakdown of complex SQL statements into smaller parts run sequentially may increase query speed. Each part accesses 1 or 2 tables to create a temporary table (or view). These (smaller) temporary tables are then joined [3]. Depending on the ability of the database engine to devise an efficient search strategy, the overall query speed may benefit from creating and joining smaller temporary tables compared to self-joining the full EAV table. An efficient database engine should, however, itself be able to optimize the original query, so that little is gained from this approach. In the MySQL database described above, the creation of a single temporary table took longer (more than 30 seconds) than the execution of the full 3-attribute search (24 seconds).
- Johnson et al [10] suggest an extension to the SQL-query language to facilitate "pivoting" of attribute-centered data into a conventional layout—the Extended Multi-Feature (EMF) SQL. Extended Multi-Feature SQL processing time is linearly proportional to number of attributes.

In summary, querying EAV data is a more complex task than querying data in a conventional layout; and attribute-centered queries are less efficient with EAV data compared to conventional data.

### Graphical User Interface

The challenge for the user-interface designer of an EAV database is to display data and to let the user manipulate data simulating a conventional layout irrespective of the physical layout—in other words: to bridge the physical and the logical schemas.

The World Wide Web offers an opportunity to simplify database deployment and maintenance. In a typical Web database application, the user's browser requests data from a remote Web server, which sends the request to a database server. After receiving data back from the database server, the Web server formats it into a Web page and sends it to the client browser.

There are several advantages of Web deployment:

- Problems of form deployment are eliminated since all forms reside on the Web server.
- Deployment costs are reduced because Web browsers are available free. Also, hardware costs are reduced since browsers usually have smaller hardware requirements than desktop database-management systems do.
- The form-rendering model of Web pages is simpler and smarter than that of traditional software platforms. Objects on a Web page can be automatically reformatted when the browser window is resized or the user changes the font size. Traditional software developers must put much effort into physical screen size issues. This is not necessary with Web forms.
- Web browsers use clever caching algorithms. That means that when the browser visits a particular page, its contents are cached on the client. On revisit, only components that have changed are downloaded again. This reduces download time and network load.

For these reasons, Web deployment is becoming more and more popular for multi-user applications. However, Web database applications are significantly more complex to develop than traditional database applications for several reasons:

- Web-development tools are less mature than tools for traditional software development; and development of Web database applications still requires much "coding-by-hand." As an example, simple errors such as misspelled variable names, which would be trapped at edit or compile time in a traditional environment, will not be detected until runtime in a Web application.
- Browser-server communication is inherently stateless; when the server has sent a Web page to the client, it "forgets" about the client. Tracking information (eg, user authentication) through several Web pages therefore involves extra programming. To maintain information, the developer must store data either in (hidden) form fields on Web pages or in session variables, which can be accessed as long as the session lasts. Both approaches complicate development and may compromise security because other users (or processes) may gain access to these data intentionally or accidentally.

- Designing Web forms requires much more programming than does designing forms in traditional client-server environments. Web form fields are typeless and input masks for formatting user inputs are not inherent parts of Web forms. (In typeless fields the user may accidentally enter numbers in text-only fields or accidentally enter text in numbers-only fields.) This puts pressure on the programmer to put much effort into both client-side and server-side data validation. In a traditional environment, form fields may be typed; thus, eg, the programmer does not need to worry about users entering letters in number fields or invalid dates in date fields. In a Web form, all validation procedures must be hand coded. Finally, population of select boxes (drop-down menus) and radio buttons (option buttons) with dynamic data is usually much easier in a traditional environment than on a Web form.

Programming Web forms is tedious and error prone, and automation is highly recommended. Nadkarni et al have studied a generic framework for automatic generation of Web forms for display and manipulation of EAV data (WebEAV) [4]. The main objective was to automate the generation of Web forms based on metadata in an EAV database. When details about an event are requested, a form is generated from the metadata of the attributes involved. Each form field has a unique name, which is constructed such that the field name contains its own metadata. When data is sent back to the server, the server creates the correct SQL statements by parsing field names, and data are updated accordingly.

WebEAV makes extensive use of client-side validation of data. Standard validation code in the form of JavaScript is built into the Web page. Validation relies on the use of form field events (eg, OnChange, OnFocus, and OnBlur) and metadata for the attributes in the form (eg, data type, maximum and minimum bounds, and non-null requirements).

## Discussion

Based on searching the literature, it appeared that the Entity-Attribute-Value model is useful for generic design of clinical databases. The most advanced model uses an object-oriented approach and gives tremendous flexibility, allowing the designer to model any type of concept and any relation between concepts in the domain of interest without ever having to worry about changing the table layout or maintaining the user interface. With the ever changing and evolving domain of clinical information, generic design is of special interest for clinical databases, because changes to the logical schema will not affect the physical schema. However, database designers from other areas (eg, biology or literature) may also find the EAV approach useful.

Historically, EAV was introduced into clinical databases in TMR (The Medical Record), built at Duke in the 1970s [13,14]. In addition to the ones mentioned in this paper, production databases using EAV components include TrialDB [14], the HELP system [15], the Cerner and 3M repositories, ClinTrial, and Oracle Clinical.

### Pros and Cons of EAV Design

The advantages of generic design are obvious. The disadvantages, however, may be less obvious and depend on the objectives of the specific application in question.

From a performance point of view, the strength of the EAV design lies in effective entity-centered queries since no joins are necessary to retrieve all facts about entities (eg, patients or medical events) as would be the case in a conventional design with facts spread over hundreds of tables. The drawback lies in inefficient attribute-centered queries, since a (self) join is necessary for each attribute that is requested.

Performance of EAV tables may not be an issue for small databases, but for large clinical repositories with hundreds of concurrent users, query time may be a critical factor. Also, the need for complex attribute-centered data retrieval differs greatly between applications. An electronic patient-record system, for example, is usually aimed at displaying patient-centered (ie, entity-centered) facts, while a research database usually must have some means of aggregating data across a large number of patients. In the latter, however, query efficiency may not be a problem, since data summaries are retrieved only intermittently and may be stored on separate hardware.

These issues warrant careful design of the database schema and cautious decisions about when to use conventional tables in place of generic EAV tables. As a rule of thumb, conventional table design is appropriate for entities whose schemas are not expected to change often (eg, people or institutions).

### Metadata Preserves Information

The simplicity and flexibility of the database schema also increases the complexity of collecting and displaying information from data. The user needs to see and enter related data on the same form. Often single values do not make sense unless coupled with other values. Take as an example a body weight of 176 lb (80 kg). This would be perfectly normal (and desirable for some of us) for an adult male with a height of 5 ft, 10 in (182 cm). For a 10-year-old girl, 176 lb would be highly disturbing. Using a simple EAV data table layout, relations between data are lost unless steps are taken to store these as well. This is the whole idea of metadata—to conserve information about relationships between atomic data values. The metadata schema is the only thing that differs between the different EAV models presented in Figure 1, Figure 2, and Figure 3 and between the actual implementations of the EAV model presented in the articles. The data parts are for practical purposes the same.

It appears that metadata schemas themselves may be more or less generic depending on how closely related they are to the actual domain being modeled. The more specific the metadata schema is, the less flexible it will be. On the other hand, a specific metadata schema will require less programming to drive the user interface than a highly generic one.

To summarize this part, the choice of model depends on the domain and the requirements for flexibility. The object-oriented approach is by far the most flexible solution and in many ways an elegant solution. On the other hand, the complexity introduced by this model may not be justified unless the domain requires the fine-grained control over objects and relations. A simple model may well be the right solution for a simple job.

## Databases and Objects

Much effort has been put into generalizing clinical databases. The most flexible and generic models take an object-oriented approach to data modeling the mapping of objects to tables in a relational database. There is no doubt that object-oriented design is "hot" in the medical area. But porting of object-oriented generic databases from traditional relational databases to produce object-oriented database management systems (OODBMSs) does not seem to be just around the corner. One reason for this may of course be that object-oriented database management systems are still lagging behind relational database management systems with respect to efficiency and availability, although extensive research is going on in this field. Furthermore, object orientation is still a new concept to most clinicians who design databases. But even with modest skills in an object-oriented programming language such as Java, the similarities between object-oriented programming and object-oriented data management seem striking.

Object-oriented databases come in two flavors [16]:

- Systems that provide object-oriented extensions to relational systems by adding composite attributes, class hierarchies, and extensions to a data manipulation language such as SQL. These systems are called *object-relational* systems.
- Systems that extend an existing object-oriented programming language like C++ or Java to deal with databases. Such languages are called *persistent* programming languages. The term "persistent" refers to the fact that the programming language must devise some means of storing objects even when the program is not running. Databases built upon persistent programming languages are called *object-oriented* databases.

The former approach has similarities to the approaches described in this project in that these build upon conventional relational database management systems. The SENSELAB database allows for composition and inheritance, and CPMC has explored the extension of SQL to facilitate attribute-centered querying EAV data.

The latter approach to *generic* database design has to my knowledge not been described in the medical literature. The idea of encapsulating all data and functionality relevant to an object within each object opens up a plethora of possibilities of interest for the developer and manager of clinical information systems:

- The object-oriented paradigm ("everything is an object") is a means of describing real-world concepts, and objects may be easier to understand for a clinician than complex relationship sets in a relational database. One could say that object-oriented design brings together the logical and the physical schema. Even if this may not be completely true, the user should not have to worry about how to design tables for storing of objects. The database will take care of this.
- Object-oriented languages handle complex attributes and inheritance much more elegantly than do even the most cleverly-designed relational database. When referring to an object in an object-oriented programming language, the object's fields and methods are available to the user immediately, through the object's interface. To mimic an object in a relational database, the database must be queried for all attributes of interest, and each value must be accessed separately.
- Objects may contain methods. For example, a person object may contain a print() method, which outputs all information related to the objects in a suitable format. The client programmer, who builds the user interface, does not have to worry how this information is gathered. This programmer only needs to grab the information and present it in a nice layout on a form. Furthermore, different subtypes of the person class, eg, patient or doctor, may have different implementations of the print() method. This is an example of polymorphism and is one of the most powerful features of object-oriented programming languages.
- Classes may be reused. If a class has been designed, it may be reused in other applications; and if a class is redesigned (eg, to improve execution speed) the client programmer does not need to know this, as long as the class' interface is unchanged.

A detailed discussion of object-oriented programming is outside the scope of this article. However, the power of object-oriented programming may be summarized in the terms *encapsulation* and *polymorphism*. Encapsulation means that an object knows all about itself and that it interacts with the surroundings only through a well-defined interface. Encapsulation facilitates reuse and safe programming. Polymorphism means "having many forms." A polymorphic reference is one that can refer to objects of different (sub) types at different times, which is exactly what we need in a generic database.

It is obvious that these (and other) facilities of object-oriented programming languages would be of immense value in the creation of generic clinical databases. It is, however, important to realize that a database management system, whether object-oriented or not, comprises much more than a programming and query language—important issues being storage management, transaction management and concurrency control—and these issues are still under development in object-oriented database management systems. (Concurrency control involves locking parts of the database to prevent unintentional overwriting of data.)

## Conclusions

The objective of generic database design is to provide a robust physical database schema that does not need to change as the domain evolves. Generic databases are of special interest for clinical information systems, and several approaches to generic design have been exercised. They have in common the use of Entity-Attribute-Value tables for storing data and a number of metadata tables to describe the semantics and the relations between data. An object-oriented approach to generic modeling of metadata is by far the most flexible and domain-independent approach. However, the overhead in taking this approach may not be justified for less-advanced applications.

Further studies regarding the implementation of object-oriented database management systems for the purpose of generic clinical databases are suggested.

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## Conflicts of Interest

None declared.

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## Abbreviations

**ACT/DB:** Adaptable Clinical Trials DataBase
**CPMC:** The Clinical Data Repository at Columbia-Presbyterian Medical Center
**EAV:** Entity-Attribute-Value
**EAV/CR:** EAV with Classes and Relations
**SQL:** Structured Query Language

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Original Paper

# Reasons for Consulting a Doctor on the Internet: Web Survey of Users of an Ask the Doctor Service

Göran Umefjord[1], MD; Göran Petersson[2], MD, PhD; Katarina Hamberg[3], MD, PhD

[1]Nyland Health Center, Biskopsgatan 1, SE-870 52 Nyland, Sweden
[2]Department of Otorhinolaryngology, Lund University, Sweden, Now at Swedish Net University Agency, Härnösand, Sweden
[3]Department of Public Health and Clinical Medicine, Family Medicine, Umeå University, Sweden

**Corresponding Author:**
Göran Umefjord, MD
Nyland Health Center
Biskopsgatan 1
SE-870 52 Nyland
Sweden
Phone: +46 612 771500
Fax: +46 612 22962
Email: umefjord@ymex.net

## Abstract

**Background:** In 1998 the Swedish noncommercial public health service Infomedica opened an Ask the Doctor service on its Internet portal. At no charge, anyone with Internet access can use this service to ask questions about personal health-related and disease-related matters.

**Objective:** To study why individuals choose to consult previously-unknown doctors on the Internet.

**Methods:** Between November 1, 2001, and January 31, 2002 a Web survey of the 3622 Ask the Doctor service users, 1036 men (29%) and 2586 (71%) women, was conducted. We excluded 186 queries from users. The results are based on quantitative and qualitative analysis of the answers to the question "Why did you choose to ask a question at Infomedica's 'Ask the Doctor' service?"

**Results:** 1223 surveys were completed (response rate 34%). Of the participants in the survey 322 (26%) were male and 901 (74%) female. As major reasons for choosing to consult previously-unknown doctors on the Internet participants indicated: convenience (52%), anonymity (36%), "doctors too busy" (21%), difficult to find time to visit a doctor (16%), difficulty to get an appointment (13%), feeling uncomfortable when seeing a doctor (9%), and not being able to afford a doctors' visit (3%). Further motives elicited through a qualitative analysis of free-text answers were: seeking a second opinion, discontent with previous doctors and a wish for a primary evaluation of a medical problem, asking embarrassing or sensitive questions, seeking information on behalf of relatives, preferring written communication, and (from responses by expatriates, travelers, and others) living far away from regular health care.

**Conclusions:** We found that an Internet based Ask the Doctor service is primarily consulted because it is convenient, but it may also be of value for individuals with needs that regular health care services have not been able to meet.

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**KEYWORDS**

Internet; remote consultation; physician-patient relations; access to information; information services; anonyms and pseudonyms

## Introduction

Internet-based health services offer health information, including advice from health care providers, to individuals. A new service of that type is consultation with a doctor. Until now, these consultations have been mainly text-based, using communication by e-mail or by Internet servers. When the inquirer and the doctor already know each other e-mail has been the main method of communication.

Internet based Ask the Doctor services offer an opportunity for users to contact doctors they have never met. In these consultations, the inquirer may remain anonymous. We use the term *Internet doctor* for a doctor performing consultations on the Internet without any previous contact with the inquirer.

Internet consultations without a pre-existing relationship give rise to a number of questions: Why would the individual consult an Internet doctor who will have limited knowledge of the individual's medical and social background and who cannot perform a physical examination? Can this type of Internet consultation cause harm? What role will Internet consultations play in parallel with regular health care?

The experiences and benefits of Internet consultations between patients and doctors are not widely explored. In a pioneering study, conducted in 1997, Eysenbach [1] analyzed 209 questions sent by e-mail to a university dermatology hospital. The researchers found that a majority of the inquirers wanted a second opinion (while only 5% had not seen a physician before the inquiry), and that almost 1 of 5 expressed frustration with their previous patient-physician relationship. Of the inquirers, 44% asked for themselves, while 30% asked on behalf of a family member or friend. As possible reasons for why people turn to "unknown" physicians with their questions Eysenbach discusses: frustration with and lack of trust in their own physician, inadequate information received from their own physician, coping, irrational hopes, anonymity (which encourages asking embarrassing questions), and looking for information on behalf of others. Borowitz et al analyzed 1239 questions e-mailed to a unit for pediatric gastroenterology and found that the majority of the questions were sent by parents and were about the most-common intestinal disorders [2]. Legal, ethical, and clinical aspects of e-mail consultations are addressed in several papers [1,3-12]. Recently, 8 years of experiences from an Internet-based remote medical counseling project by e-mail have been described by Labiris et al [13].

With regard to consultations with Internet doctors, the experiences are primarily derived from analyzing e-mail inquiries, sometimes from situations where patients and family members write to physicians "uninvited" (unsolicited e-mail) [1]. In the present paper we studied why individuals chose to consult an "Ask the Doctor" service on the Web.

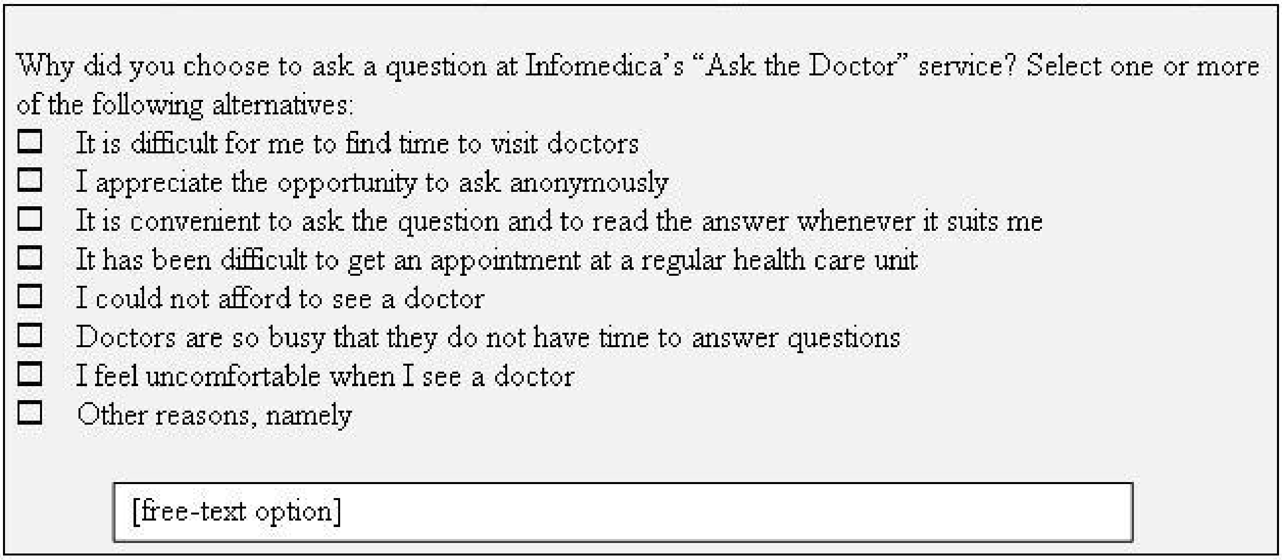
## Methods

In 1998 the Swedish noncommercial public health service Infomedica [14] opened an Ask the Doctor service on its Internet portal. At no charge, anyone with Internet access can use this service to ask questions about personal health-related and disease-related matters. The inquirer can be anonymous. Any kind of personal medical issue can be addressed without any predefined rules for the inquirer except for the mandatory input of age group and gender. Each question is answered within 7 days by experienced family doctors. Before the answer is published, it is reviewed by a coordinator. The answer is retrieved using a password. Nonpersonal or essay-type questions are rejected and responded to by a standard answer instead of being answered by an Internet doctor.

Between November 1, 2001, and January 31, 2002, all inquirers at Infomedica's Ask the Doctor service were invited to take part in a survey. The inquirers were informed of the survey when posing their medical question. While receiving the Internet doctor's answer on the Internet, in a separate Web-browser window the inquirer was invited to answer the question "Why did you choose to ask a question at Infomedica's 'Ask the Doctor' service?" with 7 multiple-choice alternatives and a free-text option (Figure 1). The inquirer was informed that the survey was anonymous with no possibility of the answers being traced to the respondent. The study was approved by the Umeå Clinical Research Ethics Committee, Umeå, Sweden.

In the present paper the term *inquirer* is used for an individual who posed a question to the service, and the term *participant* is used for a member of the subgroup of inquirers that also completed the survey.

**Figure 1.** The question to be answered by the individuals using the Ask the Doctor service, with response alternatives



Why did you choose to ask a question at Infomedica's "Ask the Doctor" service? Select one or more of the following alternatives:

☐ It is difficult for me to find time to visit doctors
☐ I appreciate the opportunity to ask anonymously
☐ It is convenient to ask the question and to read the answer whenever it suits me
☐ It has been difficult to get an appointment at a regular health care unit
☐ I could not afford to see a doctor
☐ Doctors are so busy that they do not have time to answer questions
☐ I feel uncomfortable when I see a doctor
☐ Other reasons, namely

[free-text option]

### Participants

During the period of the survey a total of 3622 inquirers, 1036 men (29%) and 2586 (71%) women, used the service. Inquirers completed 1223 surveys, a response rate of 34%. It was not possible to exclude enquirers who may have posed more than 1 question to the service during the 3 months of the survey, or who may have participated in the survey more than once. There were 186 nonpersonal or essay-type questions that were rejected. Of the participants in the survey, 322 (26%) were men and 901 (74%) women. A few (n = 34) individuals who entered the study neither selected a multiple-choice alternative nor filled in the free-text box.

The inquirers indicated their age in 5-year ranges while submitting their medical question. Thus, the mean age of the inquirers could not be computed exactly, but the approximate mean age was 37 years (men: 37; women: 39) and the approximate median age of the inquirers was 35 years (men: 36; women 34). In the survey the participants defined their year of birth. The mean age for the participants was 41 years (range 8-88; men 45; women 40) and the median age was 38 years (men: 44; women: 38). Of the participants, 18 did not enter their year of birth.

### Analysis

Because the analyzed response was a combination of multiple-choice alternatives and a free-text option, both a quantitative analysis and a qualitative analysis were performed. The frequencies of the multiple-choice alternatives were computed using the software Publech version 3.0 (Ntech, Sundsvall, Sweden). The free-text answers were analyzed using a grounded theory approach [15]. After transcription the answers were read and coded for meaning and content by 2 of the researchers separately, then recoded by the 2 researchers together. Codes were discussed and sorted into categories. The reliability of the coding and categorization was discussed at a seminar by a group of researchers not involved in the study. As a result of their comments minor changes were made in the categorization.

## Results

### Multiple-choice answers

One third of the participants selected 1 multiple-choice alternative whereas two thirds selected 2 or more multiple-choice alternatives and/or gave a free-text answer (Table 1). The most frequently chosen alternative to the question "Why did you choose to ask a question at Infomedica's 'Ask the Doctor' service?"—selected by half of the participants—was convenience (Table 2). More than one third of the participants selected anonymity. Only 38 participants selected financial reasons.

**Table 1.** Distribution of selected multiple-choice and free-text alternative responses to the question in Figure 1*

| Multiple-choice Alternatives Chosen †, Number | Participants, Number |
|---|---|
| Only multiple-choice alternative(s) chosen: | |
| 1 | 380 |
| 2 | 252 |
| 3 | 136 |
| 4 | 47 |
| 5 | 13 |
| 6 | 1 |
| 7 | 0 |
| Only free-text option used | 177 |
| Both multiple-choice alternative(s) chosen and free-text option used | |
| 1 | 108 |
| 2 | 46 |
| 3 | 23 |
| 4 | 3 |
| 5 | 3 |
| 6 | 0 |
| 7 | 0 |
| Neither multiple-choice alternative chosen nor free-text option used | 34 |
| Total | 1223 |

[*] The question was: "Why did you choose to ask a question at Infomedica's 'Ask the Doctor' service?"

[†] Participants were instructed to choose 1 or more of the multiple-choice alternatives and were given the option of entering free text.

**Table 2.** Number and percentage of responders to the selected alternative responses the question in Figure 1*

| Multiple-choice Alternative Chosen † | Number | % |
|---|---|---|
| It is convenient to ask the question and to read the answer whenever it suits me | 640 | 52 |
| I appreciate the opportunity to ask anonymously | 437 | 36 |
| Doctors are so busy that they do not have time to answer questions | 262 | 21 |
| It is difficult for me to find time to visit doctors | 201 | 16 |
| It has been difficult to get an appointment at a regular health care unit | 163 | 13 |
| I feel uncomfortable when I see a doctor | 106 | 9 |
| I could not afford to see a doctor | 38 | 3 |
| Subtotal | 1847 | |
| Other reasons, entered in [free-text option] | 360 | 29 |
| Total | 2207 | |

* The question was: "Why did you choose to ask a question at Infomedica's 'Ask the Doctor' service?"

† Participants were instructed to choose 1 or more of the multiple-choice alternatives and were given the option of entering free text. There were 1223 participants.

## Free-text answers

More than one fourth, 360 participants, chose to use the free-text box. In the qualitative analysis these answers were coded and sorted into the following 6 categories, listed in order of decreasing prevalence. Some of the answers included more than one reason and were sorted into more than one category.

### *Second Opinion (in 110 of 360 free-text answers, 31%)*

A wish for a second opinion was the most-common reason among the free-text answers, expressed by more than one fifth of the participants. Many just wrote the words "second opinion" while others gave a more detailed explanation, for example, "It is good to ask someone else. Everyone does not have the same opinion." Several of the free-text answers disclosed that family members wanted a second opinion on behalf of relatives.

### *Discontent With Previous Doctors (89/360, 25%)*

Almost as frequent as wanting a second opinion were answers expressing discontent with health care previously received and in particular discontent with doctors. Many participants complained that their doctor "did not know the answer" or that doctors had "given contradictory answers." Others claimed that their doctor "did not care," "did not listen," "was short of time," "was nonchalant," "was negligent," or "did not rack his brain with the problem." Some participants complained that the doctor was "hard to understand" because of language difficulties.

### *Primary Evaluation of a Medical Problem (53/360, 15%)*

In this category, some respondents wanted to know if it was necessary to visit a physician at all. Some participants were uncertain if their question was severe enough to bother a doctor at his/her clinic, for example, "feeling foolish, it might not be serious." Others wanted deeper knowledge of body functions claiming that this was not often accomplished while seeing a physician. In a few cases the reason for asking was the explicit wish of remaining autonomous and taking care of the health issues oneself, for example, "wanted to check if I could do anything myself without seeing a doctor." Some wanted to get further knowledge before an appointment, for example, "I want to prepare myself before visiting my doctor. Get knowledge. Get alternative points of view."

### *Convenience, Distance, and Time (49/360, 14%)*

Although it was a multiple-choice alternative, some participants also used the free-text option to express their satisfaction with the possibility of using a computer to pose their question whenever it suited them, for example, "This is faster and it is more convenient to use the computer." Some lived in rural areas with few doctors. At least 10 of the participants were Swedes living abroad wanting to consult a doctor in their native language. Discontent with access to regular health care was also a frequent complaint. Some had been offered an appointment with a doctor in the distant future but did not want to wait that long.

### *Embarrassing Concerns and Worries (16/360, 4%)*

A few participants expressed their appreciation for the option of getting answers to embarrassing questions, for example, "I feel that my problems are a bit awkward." Others stated worry as the main reason for asking, "still worried although I have already seen a doctor" and in a couple of cases also presented himself/herself as a hypochondriac.

### *Preference for Written Communication (15/360, 4%)*

A few participants stated that both the question and the answer could be better formulated when communicating in writing, for example, "it may be easier to get a good answer if the doctor has sufficient time to phrase it." Others found it difficult to remember what the doctor said, for example, "the consultations are so rushed that it is hard to catch all that has been said," or that a written answer can be read more than once, thereby making it easier to understand.

## Discussion

In the present study we found that, of the multiple-choice alternatives, the reasons for consulting an Internet doctor in decreasing order were: convenience; anonymity; doctors too busy to answer questions; lack of time to visit a doctor; difficult to get an appointment; feeling uncomfortable when seeing a doctor; and financial reasons. In the free-text answers the reasons found were: second opinion; discontent with previous doctors; primary evaluation of a medical problem; convenience, distance and time; embarrassing concerns and worries; and preference for written communication. Half of the participants chose to give more than one reason for asking a doctor on the Internet. It is not relevant to directly compare the frequencies of the multiple-choice answers with the frequencies of the free-text answers, because the threshold for writing a free-text answer is higher than the threshold for choosing a multiple-choice alternative.

### Methods

The age profile of both the inquirers and the participants in the present study differs from the one seen in regular health care. The age of the majority of the inquirers of the Ask the Doctor service was 21-40 years. In spite of a low response rate the largest number of completed surveys also originated from this age group. Internet use has been found to be markedly age-related with the highest rates among youths and young adults [16- 17].

As men are regarded as more technology oriented than women, one might expect that men were more prone to use an Internet based Ask the Doctor service than women. However, during the period of the survey the use was dominated by women, with almost 3 out of 4 (71%) inquirers being women, thus exceeding the difference seen in regular Swedish health care. This gender difference corroborates other studies that have shown that women are more likely than men to go online to seek health-related information [18].

Internet users are a selected sample of the population. Sampling error (surveying a sample rather than the entire population) is a general dilemma in research and is a more pronounced problem in online research. The participants of the present Web survey chose to turn to the Internet with their medical issues. It is likely that they felt more positively about Internet based consultations than a population that has never considered the possibility of consulting an Internet doctor would. In line with this, the conclusions of the present survey should not be generalized to the population as a whole, but only to Ask the Doctor users who chose to participate in our survey. It is possible that the 66% of users who did not answer the survey had different reasons for consulting the service.

One of the advantages of Web surveys is that the effort required for gathering even large amounts of data is minimal. In our study 1223 surveys were completed. A disadvantage of Web surveys is the low response rate, in our survey 34%. Response rates in Web surveys are generally low, often far lower than in the present survey [19]. The shorter the survey is, the higher the response rate is likely to be. Trying to achieve an acceptable response rate in a Web survey while still being able to gather sufficient information is a question of balance. Our solution to this question was to combine quickly-entered multiple-choice answer options with an open-ended text box. As a result, the survey could be completed within a few minutes. A risk with this combination is that the multiple-choice alternatives presented before the free-text option could bias the free-text answer.

In the free-text responses we found some important information not included in the multiple-choice alternatives, thus the free-text option fulfilled its purpose.

The reliability of Web surveys compared to paper-and-pencil questionnaires can be disputed. In a comparative study of personality questionnaires performed either with paper-and-pencil or on the Internet there were no important differences to be found [20]. Another study compared patients' experiences of their physician's counseling using parallel telephone and Web surveys with exactly the same questions [21]. All the responses were uniform with the exception that the online participants were more overtly negative to previous counseling by their physicians than the telephone respondents were, suggesting that a spoken dialogue may restrain negative opinions. In the free-text responses of the present study we also found that a considerable number of the participants were overtly dissatisfied with previous performances of physicians. Thus, Web surveys could be an alternative to consider when it is important to get answers on sensitive issues such as an evaluation of the performance of a doctor.

### Results

Because computers are easily accessible, in homes as well as in workplaces, in most developed countries it is easy to understand why convenience was a major reason for participants choosing Internet consultations. Furthermore, the asynchronous access to the Internet based Ask the Doctor service allows users to access the service at times they find convenient, a feature appreciated by many of the participants.

In the Internet consultation the individual may remain anonymous thereby allowing inquirers to ask, eg, sensitive and embarrassing questions. In our study more than one third of the participants appreciated the opportunity of being able to ask anonymously, suggesting that this feature may supplement regular health care. In previous studies "health seekers" also appreciated the anonymity of searching the Internet for medical information [22,23].

A further reason given for using an Internet based Ask the Doctor service was, not surprisingly, the wish to be better informed. In spite of having previously visited a physician, many of the participants still had unfulfilled information demands, which corroborates earlier studies with similar results [1]. One fifth of the participants found doctors to be too busy to answer questions, a finding supported by many of the free-text answers. A frequent theme in the free-text answers was discontent with physicians. Thus, as noted before [1], Ask the Doctor services may act as an arena for the dissatisfied patient.

We found that many participants expressed a need for a second opinion, which may be one of the major features that Internet

Ask the Doctor services can provide. In Sweden the right to a second opinion is granted only in the case of serious health conditions. For less-serious medical problems, or if there is a communication failure with the regular doctor, it is difficult to receive another doctor's evaluation of one's health problems.

The individual's preferred method of communication seems to be another important feature. Some participants stressed the importance of being able to reflect on both their question and the answer. Others responded that it could be difficult to understand what doctors said or that the information could be hard to remember. The complexity of today's medical situations, where there are several treatment options, could be a reason to provide more of the information in writing.

The low importance in our study of financial reasons for consulting Internet doctors is probably due to the relatively low cost of medical care for the individual in Sweden. In contrast in a study including many international inquirers 14% of the participants claimed that they could not afford local medical services [13] compared to 3% in our study of, presumably, mainly Swedish citizens.

### Limitations and Risks

A crucial issue is whether consultations on the Internet might cause harm for the involved individuals or their regular doctors. Until now there have been only a few reports on harm related to the use of the Internet [24- 25]. MedCERTAIN (now MedCIRCLE), a international collaboration of trusted organizations active in the field of rating and annotating health information, has set up a database, DAERI (Database of Adverse Events Related to the Internet) to collect such reports [26,27]. One aspect of possible harm is the risk of negative impact on the relationship between the inquirer and the inquirer's regular doctor. An insensitive answer from an Internet doctor might reduce the inquirer's confidence in the regular doctor. In a British survey, twice as many doctors reported patients experiencing benefits than problems from the Internet [28].

It has been claimed by doctors that it is preferable for all patients searching for medical advice to see a doctor in a face-to-face consultation [29]. However, in some situations individuals may instead choose to consult an Internet doctor. Some patients also want to communicate with their doctors by e-mail [30- 33].

### The Future

We can probably anticipate an increasing demand for Internet based and e-mail consultations as a component in the patients' mix of communicating with doctors, even if these services will be subject to fees [31]. The development of more sophisticated technologies including image and sound may partly overcome some of the limitations implied by the lack of a physical examination.

It is probable that different types of Internet based services will be regular parts of the services offered by most health care providers. Such a development will require ethical guidelines [9], education, and training, as well as standards concerning communication records. With regard to Internet based consultations between individuals and doctors, further studies are required to answer a number of questions: In what way do these inquirers differ from those visiting regular health care centers? Will the inquirers raise other kinds of complaints? How should health personnel, in particular doctors, adapt to this new situation?

## Conclusions

We found that an Internet based Ask the Doctor service is primarily consulted because it is convenient, but that it may also be of value for individuals with needs that regular health care services have not been able to meet. The Internet based Ask the Doctor service we studied provided an arena for sensitive questions, for individuals seeking advice on behalf of relatives, and for inquirers preferring written communication. In spite of the limitations implied by their lack of a personal meeting and a physical examination, Internet based Ask the Doctor services are of value for individuals with needs that regular health care services have not been able to fully satisfy.

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## Authors' Contributions

GU and GP were responsible for the study design and the Web survey. GU and KH were responsible for the qualitative analysis. GU, KH, and GP were responsible for the combined analysis, and writing of the paper. GU reviewed the literature and wrote the initial draft.

## Conflicts of Interest

GU serves as 1 of 33 paid Internet doctors and as 1 of 6 coordinators at Infomedica's Ask the Doctor service.

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Original Paper

# Adolescents Searching for Health Information on the Internet: An Observational Study

Derek L Hansen[1], BS; Holly A Derry[2], MPH; Paul J Resnick[1], PhD; Caroline R Richardson[3], MD

[1]School of Information, University of Michigan, Ann Arbor MI, USA

[2]Health Media Research Laboratory, University of Michigan Comprehensive Cancer Center, Ann Arbor MI, USA

[3]Department of Family Medicine, University of Michigan Medical School, Health Services Research and Development, VA Medical Center, Ann Arbor MI, USA

**Corresponding Author:**
Derek L Hansen, BS
2389 Stone Rd
Ann Arbor MI 48105
USA
Phone: +1 734 764 1008
Fax: +1 734 647 8045
Email: shakmatt@umich.edu

## Abstract

**Background:** Adolescents' access to health information on the Internet is partly a function of their ability to search for and find answers to their health-related questions. Adolescents may have unique health and computer literacy needs. Although many surveys, interviews, and focus groups have been utilized to understand the information-seeking and information-retrieval behavior of adolescents looking for health information online, we were unable to locate observations of individual adolescents that have been conducted in this context.

**Objective:** This study was designed to understand how adolescents search for health information using the Internet and what implications this may have on access to health information.

**Methods:** A convenience sample of 12 students (age 12-17 years) from 1 middle school and 2 high schools in southeast Michigan were provided with 6 health-related questions and asked to look for answers using the Internet. Researchers recorded 68 specific searches using software that captured screen images as well as synchronized audio recordings. Recordings were reviewed later and specific search techniques and strategies were coded. A qualitative review of the verbal communication was also performed.

**Results:** Out of 68 observed searches, 47 (69%) were successful in that the adolescent found a correct and useful answer to the health question. The majority of sites that students attempted to access were retrieved directly from search engine results (77%) or a search engine's recommended links (10%); only a small percentage were directly accessed (5%) or linked from another site (7%). The majority (83%) of followed links from search engine results came from the first 9 results. Incorrect spelling (30 of 132 search terms), number of pages visited within a site (ranging from 1-15), and overall search strategy (eg, using a search engine versus directly accessing a site), were each important determinants of success. Qualitative analysis revealed that participants used a trial-and-error approach to formulate search strings, scanned pages randomly instead of systematically, and did not consider the source of the content when searching for health information.

**Conclusions:** This study provides a useful snapshot of current adolescent searching patterns. The results have implications for constructing realistic simulations of adolescent search behavior, improving distribution and usefulness of Web sites with health information relevant to adolescents, and enhancing educators' knowledge of what specific pitfalls students are likely to encounter.

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**KEYWORDS**

Internet; adolescent; access to information; medical informatics; computer simulation; computer literacy; health education; search process; information seeking; information storage and retrieval

## Introduction

The Internet has become an important tool for many people with health concerns [1,2], especially for adolescents [3,4]. Concerns about confidentiality, coupled with the fact that many teenagers find accessing care through traditional providers difficult [5], make access to information via the Internet particularly important. Given rapidly-expanding Internet access among young people, it is not surprising, then, that more than 70% of 15 to 17 year-olds say they have used the Internet to look up health information (written communication, 2001 Dec; Generation RX.com Survey printouts; V. Rideout, Henry J. Kaiser Foundation, Menlo Park, CA). This percentage is likely to increase if Internet access from home continues to rise as it has in recent years [6].

Because of the enormous amount of unstructured online content, it is crucial to understand how youth navigate through the Web to find health information. Prior research, primarily from library and information science literature and education literature, has highlighted several search characteristics that are either unique or more pronounced in adolescents. For example, adolescents take more time to complete online tasks than college students [7], search less systematically [7- 10], have difficulty formulating search queries due to misspelling and problems with the level of specificity [8- 11], utilize less-advanced search syntax [7], and rarely consider the source of Web pages [8,9]. While informative, this literature is based primarily on adolescents searching for answers to homework questions rather than health information.

Searching for online health information involves distinctive challenges including unfamiliar terminology [12]; encounters with pornography-blocking software (written communication, 2001 Dec; Generation RX.com Survey printouts; V. Rideout, Henry J. Kaiser Foundation, Menlo Park, CA), [13]; and the importance and difficulty of determining health information quality [14]. However, despite the need for research that details the online search behavior of health consumers, the authors were only able to locate a few articles in which health science researchers actually observed, recorded, and analyzed consumers of any age searching for health information [14- 16]. Instead, surveys (eg, written communication, 2001 Dec; Generation RX.com Survey printouts; V. Rideout, Henry J. Kaiser Foundation, Menlo Park, CA; and [1,2,4]) have been the predominant method used to understand health consumers' online searching behavior, despite problems with participant recall and the inability of surveys to capture specific search tactics. In addition, the authors found a handful of studies in the medical informatics literature that have also looked at log data from particular medical Web sites, but these studies are also limited in scope since they do not observe the actual searcher or see the broader context in which the searcher is acting [17] (see also [18] for similar studies performed on search engine data). The value of directly observing users was demonstrated in the Eysenbach study, which revealed that adults said they paid attention to the source of health sites during interviews, although this behavior was not found during the actual observations [15].

Observational research specific to the adolescent age group and online search behavior for health information is also sparse. There have been some good surveys that answer many useful questions concerning why adolescents go to the Internet, what they search for, if they find it, and what they do with it (written communication, 2001 Dec; Generation RX.com Survey printouts; V. Rideout, Henry J. Kaiser Foundation, Menlo Park, CA;and [4,19]). The only observational study we were able to locate conducted 27 focus groups where groups of adolescents searched online for health information as they discussed their own experiences [14]. Many of the findings concerning adolescent search behavior found in the library and information science literature were confirmed and additional issues were raised, including concerns about low health literacy and trouble judging the quality of information, that may be more pronounced in adolescents than adults. However, that study only begins to paint a picture of adolescent search behavior for online health information, because the searches were performed in a group setting and the success, failure, and specific search tactics used were not coded or analyzed.

The study reported here provides a more in-depth understanding of how adolescents search for health information using the Internet and what implications this may have on access to health information. To capture enough detail, the study recorded specific actions taken by adolescents which were later coded and analyzed. Participants were encouraged to share their thought process out loud as they searched for answers to a list of predetermined health questions. The result was a rich set of both quantitative and qualitative data that was thoroughly analyzed for common themes and events. Specific questions of interest include, but are not limited to: What are the various search strategies used? What factors contribute to finding correct and useful answers? When using a search engine, how many results pages are viewed and utilized? What types of search strings are entered into search engines? Answers to these and related questions should be of interest to a number of parties including educators (eg, health educators, librarians, teachers), Web site and search engine designers, health care practitioners, and researchers (eg, to create a sample of URLs by simulating online searching behavior [20]).

## Methods

### Sample

Twelve students from 1 middle school (N= 4) and 2 high schools (N = 4 and N= 4) in southeast Michigan were recruited for this study. Staff at each school were asked to select 4 students who were (a) comfortable using computers, (b) comfortable searching for information on the Internet, and (c) strong students who could afford to miss one class period. Students received a University of Michigan T-shirt, valued at roughly $8, in return for their participation.

The parent or guardian of every student signed an informed consent document that described the purpose and procedure of the study. Students also signed separate assent forms with similar information. The University of Michigan Behavioral Science Institutional Review Board approved this study and the consent and assent documents.

## Data Collection

Three methods of data collection were used. First, one of the two members of the research team present during each of the observations coded searching behavior in real time while the second member of the research team interacted with the student. Second, TechSmith Camtasia 3.0.1 commercial tracking software [21] was installed on the computer. This software captured the students' voices and took pictures of the screen (screen captures) twice per second during the entire session. Finally, a video camera was positioned to capture the screen and the students' voices, but not the students' images. Observations coded in real time were used to develop a more detailed and systematic coding system for use when reviewing the tracking software records. It is data from the tracking software coding that is reported here.

All observations of adolescents were conducted during January 2002. Each school provided a room in which to conduct the observations. Students were brought to the observation room one at a time. Two researchers were present at every observation. For each student, one of the researchers first reviewed the assent form to introduce the project and obtain the student's permission to participate. The students were then asked 14 questions about demographics (age, race/ethnicity, and gender) and their prior computer use (eg, how often they use computers or the Internet, what health topics they have searched, which search engines they used, and whether they have a computer and access to the Internet at home).

Once the brief interview had been completed, the observed searches began. To help the students understand the procedure and to reinforce the importance of thinking out loud while doing their searches, each student was first asked to do an easy non-health-related search looking for the next day's local weather forecast. As with the subsequent health-related searches, the local-weather question was first read to the student by a researcher and then a card with the question on it was set next to the computer in case the student needed to read it. As part of the think-aloud protocol, the experimenter asked the student to talk out loud about what they were doing, so that researchers could better understand the reasons behind the searching behavior. If a student stopped talking during the search, he or she was reminded by the observers to "keep talking," but the experimenters did not ask students to elaborate on any specific thing they said. Concurrent verbal reports more accurately reflect a subject's mental state at the time of observed behaviors than do retrospective reflections, and this minimal think-aloud protocol has been shown to slow subjects down, but not to qualitatively change their problem solving behavior [22].

After the students completed the practice local-weather search, they were given a sequence of up to 6 predetermined health information questions (see Table 1), 1 at a time. Questions were framed in a way that took into consideration the broader information concern that the question attempted to resolve. To eliminate confounding by learning effects between searches, we used a 6 x 6 Latin square to determine the order in which the questions were presented to the participants. The computer that students used was provided by the researchers, but connected to the school's network so that the students were protected from controversial or pornographic material by the same blocking or filtering software used by the school. The 3 different schools used 3 different filtering systems. Each observation session lasted one class period. No time limit was given for each question, but when the class period ended, any ongoing search was terminated and any remaining questions were skipped.

**Table 1.** Health-related questions

| |
|---|
| Your aunt was just told she has diabetes. She isn't sure what kinds of food she can or can't eat. Using the Internet, find some information for your aunt about what foods she should or should not eat. |
| A friend recently started taking a drug called Paxil for depression. He seems to be tired all the time, and even falls asleep in class. Use the Internet to find out if the drug might be making him sleepy. |
| Your older brother has a problem with drinking too much alcohol. He wants to go to a local Alcoholics Anonymous meeting. Use the Internet to help him find a local meeting. |
| You want to get an HIV test, but you don't want anyone to know. You also don't have any money to pay for it. Use the Internet to find a place to get a free and confidential HIV test. |
| For class, you need to learn about medicine that can help people stop smoking. Using the Internet, find the names of these medicines. |
| You are about to get a tattoo, but a friend warned you that some places spread infections like HIV and hepatitis. Use the Internet to find out if this is true. |

Topics for the health-related questions were chosen based upon responses to a survey of adolescents conducted by the Kaiser Family Foundation (written communication, 2001 Dec; Generation RX.com Survey printouts; V. Rideout, Henry J. Kaiser Foundation, Menlo Park, CA). Certain topics including homosexuality, teen pregnancy, and abortion were purposefully avoided so as not to expose participants to overly-controversial information.

## Data Analysis

After all the observations were completed, 3 researchers including a physician, health educator, and human-computer interface specialist met as a group to review the real-time coding results and to clarify or augment the coding scheme before the definitive final coding of the tracking-software records. The final coding scheme was designed to record data on the person searching, the question being asked, the time it took to find an answer, the search strategy utilized (eg, utilize search engine or directly type in URL); search strings used; number of search engine results pages reviewed; number of pages viewed within a particular site; and the use of menus, advertisements, and directories. One of the 3 coders was assigned as a primary reviewer for each of the observation sessions. The assigned primary reviewer was responsible for a detailed coding of the observation session and any coding problems were resolved in a second group discussion.

The reviewers classified each of the answers found by the students as *correct* or *incorrect*, *complete* or *incomplete*, and, for location questions only, *useful* or *notuseful*. To avoid being overly narrow in our classification of *correct* for the more open-ended questions such as the question on healthy foods for a person with diabetes, we used the following general rule for classification: to be considered correct, the content of the answer had to be the kind of information that might be discussed in a medical school or school of public health. This classification system was validated in previously-published work by the research team and resulted in a high inter-rater reliability ($\kappa = 0.84$) [13]. The more-specific questions such as the question asking about a location for an Alcoholics Anonymous meeting were considered correct if the student found a Web page listing a meeting location and time or contact phone number. Answers were complete if the students were able to answer all parts of the question. For example, if the student found a discussion about HIV transmission by tattoo parlors, but did not find an answer about hepatitis it was classified as incomplete. Useful answers pertained to location questions. An Alcoholics Anonymous meeting in another state was not useful. A summary measure classifying each search as successful, partially successful, or unsuccessful was computed using the correct, complete, and useful ratings. To obtain a rating of successful, the answer had to be complete, correct, and useful. If the student gave up before finding an answer, the search was classified as unsuccessful.

## Results

Twelve middle school students and high school students in southeast Michigan participated. Students ranged in age from 12 to 17 years old, with a mean of 14 years. Half of the students were female. Of the 12 students, 7 were white, 2 were African American, 1 was Indian American, 1 was Hispanic, and 1 was Asian American. Of the 12 students, only the 6 oldest students had searched for health information on the Internet before. The variation by age is consistent with other findings that youth age 15 to 17 years are significantly more likely to have looked up health information (32%) than youth age 12 to 14 years (18%) [23]. All of the students, however, had computers and access to the Internet at home. Students reported using a computer from 1 hour per week to 3 hours per day, with a mean of 12.3 hours per week.

Eleven students attempted all 6 searches, while the remaining student attempted 3, for a total of 69 searches. One search was not included since the Internet connection was not working properly, making a total of 68 searches that were analyzed. Searches took an average of 5 minutes and 41 seconds, ranging from just under a minute to nearly 24 minutes. This time frame is essentially the same as Eysenbach recorded for adults [15]. Although direct comparison is inappropriate since different questions were asked, the similar order of magnitude is suggestive.

### Overall Search Strategy

As students thought aloud, the researchers got a sense of what students were looking at on each page. Students seemed to skip around a lot, and didn't skim results pages or specific Web sites in any methodical or thorough ways, sometimes missing links or text that contained the answer to questions. This is also consistent with findings from non-health-related searching behavior as summarized in Hsieh-Yee [24].

**Table 2.** Distribution of pages viewed per site

| Pages Viewed Per Site | Sites | | |
|---|---|---|---|
| | n | % | Cumulative % |
| 1 | 143 | 70.4 | 70.4 |
| 2 | 27 | 13.3 | 83.7 |
| 3 | 11 | 5.4 | 89.2 |
| 4 | 8 | 3.9 | 93.1 |
| 5 | 8 | 3.9 | 97.0 |
| 6 | 2 | 1.0 | 98.0 |
| 8 | 1 | 0.5 | 98.5 |
| 9 | 1 | 0.5 | 99.0 |
| 15 | 2 | 1.0 | 100.0 |
| Total | 203 | 100 | |

Students used multiple methods to locate Web sites that they believed contained answers to the 68 questions. In 60 cases, the student started looking for an answer by visiting a search engine and entering in a search term or phrase. In 2 cases, the student started by selecting from directory menus (eg, choosing the topic *health*). In 6 cases, the student started by entering a URL (other than a search engine) directly into the browser address bar. In total, there were 215 attempts to access non-search-engine or directory Web sites. Nearly all of these attempts were made by following a link from a search engine either after a search or through the use of a directory. Of the 215 attempted site visits, 4 were broken links, 3 were blocked by the filters utilized at certain schools, and 5 were PDF files (read by Acrobat Reader) which students either could not download or chose not to download because downloading was too slow. This left 203 sites that were viewed with an average of 1.8 pages viewed per site. The distribution of pages visited per site is shown in Table 2. Note that the distribution is roughly consistent with a power law as observed in previous studies [25]. At a reviewer's request, this data was looked at on an individual student level. Students varied a great deal in the total number of visited sites. Eleven of the 12 students went only 1 page deep on the majority of visited sites. Although the individual-level data is not large enough to analyze more rigorously, the power law seems to operate on an individual level as well as the aggregate level.

Even when students found a Web site that contained the answer to a question, they did not always find the answer. One example is the Alcoholics Anonymous site [26] where 8 of the 11 students ended up while searching for a local meeting. Although there was a link to a site that contained local information, only 3 of the 8 students were able to find the link, 1 of whom only found it on the second visit to the Alcoholics Anonymous site, after viewing a total of 16 pages within the site. Similarly, 6 of the 11 students who searched for whether or not Paxil causes drowsiness visited the official Paxil site [27]. Only 3 of the 6 students were able to successfully answer the question based upon the information they found at the site. Two of them failed to find the list of side effects and 1 of them found the list but did not understand it enough (or read it carefully enough) to answer the question correctly.

## Search Engine Tactics

Seven search engines were used, including 2 meta-search engines (Dogpile and Locate.com). The meta-search engine Locate.com offers the user a number of search engines to choose from. Searches performed from the Locate.com Web site that utilized another search engine (eg, Yahoo!) are reported as if the search occurred on the destination search engine (eg, Yahoo!). Table 3 summarizes the number of times that a particular search engine was used. If a search engine was used multiple times while searching for an answer to the same question, it is only counted once. Because students occasionally switched search engines while trying to answer the same question, there are more searches using a search engine (79) than there are attempts to answer questions (68). In total, 6 of the 12 students used only Google, 1 used only Yahoo!, and the remaining 5 changed search engines at some point.

**Table 3.** Search engine usage

| **Search Engine** | **Times Used** | |
|---|---|---|
| | **n** | **%** |
| Google | 38 | 48.1 |
| Yahoo! | 13 | 16.5 |
| Ask | 12 | 15.2 |
| MSN | 7 | 8.9 |
| Hotbot | 6 | 7.6 |
| Dogpile | 2 | 2.5 |
| AltaVista | 1 | 1.3 |

A total of 132 search phrases were entered into the various search engines. Only 104 of those search phrases were unique. The most-frequent 2 phrases used were "diabetes" and "Paxil," each of which had 5 occurrences. There was an average of 3.6 words typed in per search phrase and 80% of the time there were 4 or fewer words per search phrase.

**Table 4.** Distribution of search-result links viewed

| **Bands of Search-Result Links Viewed** | **Chosen Links** | | |
|---|---|---|---|
| | **n** | **%** | **Cumulative %** |
| Results 1-10 | 137 | 82.5 | 82.5 |
| Results 11-20 | 8 | 4.8 | 87.3 |
| Results 21-30 | 11 | 6.6 | 94.0 |
| Results 31-40 | 4 | 2.4 | 96.4 |
| Results 41-50 | 4 | 2.4 | 98.8 |
| Results 51-60 | 1 | 0.6 | 99.4 |
| Results 61 or more | 1 | 0.6 | 100.0 |

Of the 132 search phrases, 30 contained at least 1 word that was misspelled (eg, "tatoo," "Alchoholics," or "smokeing"), despite the fact that students could read the correctly-spelled word on the index card containing the question. Some search engines (eg, Google) offer a feature that recommends an alternate search string with the correct spelling of a word. For example, if a student typed "alchoholics anonymous," the first page of results began with, "Do you mean 'alcoholics anonymous?'" Students were offered a new search string with correct spelling on 15 separate occasions, but only noticed and used it 6 times. The remainder of the times they used the results that were offered for the incorrect spelling. Of the 7 students who were offered corrected spelling suggestions, only 2 ever used them.

Once a search string was entered into a search engine, students varied in the number of results pages that were viewed. Students viewed only the first results page 78% of the time and 4 pages or less of results 93% of the time. Because search engines report a different number of links per page of search results, Table 4 reports how often links were selected from the first 10 results, the second 10, and so on. Only 3 blocked links were encountered during all of the searches, suggesting that blocking software did not have a significant impact on these results.

## Successful Searching Characteristics

Of the 68 questions that students attempted to answer, 7 searches were abandoned after the student gave up or, in 2 cases, when the class period ended. Of the remaining 61 searches, 47 were successful in finding a complete, correct, and useful answer to the health question and the remaining 14 were unsuccessful. Six of the unsuccessful answers were completely incorrect and not useful, 4 were useful but only partially correct, and 4 were fully correct but not useful.

Several factors contributed to the success of finding a correct, complete, and useful answer. One important factor was the individual who was performing the search. Although every student answered at least 1 question correctly there was wide variation in the number of correct answers. Two students successfully answered 6 out of 6 questions, 3 students successfully answered 5 questions, 4 students successfully answered 4 questions, and the remaining 3 students only successfully answered 1 or 2 questions. While our sample of students was too small to draw conclusions from, no distinct patterns were observed that would indicate that race, gender, Internet experience, or health searching experience were significant determinants of success. However, the older adolescents (16-17 year olds) were successful 87% of the time (26 of 30) as compared to 68% (21 of 31) for the younger adolescents.

Another important factor was the difficulty level of the questions themselves. Table 5 shows the failure rate for each question. The 4 partially-correct answers were split evenly between the Alcoholics Anonymous and tattoo questions. All 4 of the correct but not useful answers resulted from the HIV test question.

**Table 5.** Unsuccessful searches by search topic

| Search Topic | Unsuccessful Searches | |
|---|---|---|
| | n | % |
| HIV test | 8 | 38.1 |
| Paxil | 4 | 19.0 |
| Alcoholics Anonymous | 3 | 14.3 |
| tattoo | 3 | 14.3 |
| smoking | 2 | 9.5 |
| diabetes | 1 | 4.8 |
| Total | 21 | 100.0 |

Certain search actions led to sites that contained the answer more often than others. Overall, students found answers on 22% of the sites they accessed (47 of 215). They accessed sites in 5 ways. Although not often taken, the action with the highest probability of success (47%; 7 of 15) was following a link from 1 non-search-engine site (eg, www.aa-intergroup.org) to another site (eg, www.alcoholics-anonymous.org). In most of these cases, the student accessed the first site directly from a search engine. Clicking on search engine results led to a site where students found an answer 21% of the time (35 of 166). Success rates were similar for following a recommended link from a list or menu provided by the search engine (18%; 4 of 22). Directly typing in a URL, bypassing search engines entirely, was successful only 9% of the time (1 of 11). A sponsored link from a search engine was followed only once, and the student found an incorrect answer on that site.

Another contributing factor related to success was misspelling of search terms. Of the 14 completed but unsuccessful searches, 29% (4 searches) had at least 1 misspelling compared to only 15% (7 searches) of the 47 successful searches. Perhaps even more telling, both successful and unsuccessful searches with misspellings took students 1.5 minutes longer on average than searches without misspellings. Observations confirmed that some students were unable to find an answer until they discovered and corrected their misspelling, resulting in higher quality and more-relevant results.

Other search characteristics did not have statistically significant impacts on whether searches were successful, although this may have been due to small sample sizes. For example, the search engines were not significantly different in their percentages of successful searches. Similarly, the average number of words per search string was not significantly related to search success rate. (Data not shown.)

### Qualitative Analysis

Certain common behaviors of the adolescent searchers were observed which were not apparent from the quantitative analysis.

First, the students were very comfortable and confident while searching online for health information. Most students knew where they wanted to start the search and navigated using quick mouse clicks and shortcut keys. However, this characteristic was likely over-represented in our population due to their strong academic performance and Internet proficiency.

Second, several searchers did not take much time in formulating a search strategy or (when applicable) choosing search terms. Instead, these searchers seemed to type in the first search string that came to mind. If the results were not what were anticipated, another search string was typed in, sometimes without even clicking on any results from the first search string. The overall approach was a trial-and-error method with frequent backtracking. The most-common problem with search strings was that they were not specific enough. For example, 2 different students typed in the search string "hiv" when looking for a place that administers free and confidential HIV tests.

Third, most students quickly scanned pages, jumping from place to place within a page, rarely reading an entire paragraph. In some cases the answer to a question was contained on a page, but the student left before finding it. In other cases a link that would have led to the answer was missed. This finding supports prior research on adolescent search behavior related to nonhealth topics [7- 10].

Fourth, students mentioned that they purposefully avoided sponsored links and advertisements, despite the fact that many of the search engines present these results first. The qualitative data confirmed this practice, as only 1 sponsored link was ever selected.

Finally, little to no attention was paid to the source of the answer. In the vast majority of cases, once an answer was located, it was simply assumed to be correct.

## Discussion

When compared with prior research, the findings of this study show many similarities and a few key differences between the behaviors of adolescents and adults while searching for health information. This study found that adolescents searching for health information utilized search engines nearly every time. This finding was similar to that for adults as described in the Eysenbach study [15]. These observational studies also suggest that after-the-fact survey questions concerning the use of search engines may underestimate this behavior. For example, 2 nationally-representative surveys reported that 58% of youth (written communication, 2001 Dec; Generation RX.com Survey printouts; V. Rideout, Henry J. Kaiser Foundation, Menlo Park, CA) and 81% of adults [1,2] started seeking health information at search engines. Our study found that adolescents relied upon links from only the first few results pages, and rarely explored far within any site. These results also were similar to adult searching behaviors [15], although youth seem to be more likely to search beyond the first 10 search results. Adolescents often chose search strings that were too general and/or contained misspellings, so that they did not always find useful sites that were available. Eysenbach also reported search strings by adults that were too general [15], however, spelling seems to be more of a problem with youth. Adolescents were unsystematic in their reading of Web sites and some sites were poorly organized so that they did not always find the information they were looking for, even when it was present in a site they examined. Future research is needed to better understand if adolescents do not understand information provided on these sites, whether they simply have less patience, or some other explanation. In summary, many of the specific search tactics are similar for adults and adolescents, but a few issues related to spelling, browsing of Web sites, and understanding of content are notably different.

### Simulation of Searches

The results from this study have implications for anyone who simulates adolescent health searches, for providers of health information, and for educators. There are many reasons to simulate adolescent health searches. For example, an educator preparing a lesson plan may want to informally simulate searches in order to anticipate what students are likely to find if given certain particular search tasks. A researcher may want to simulate adolescent searches more systematically to evaluate the availability and accessibility of information on particular topics, to evaluate which search engines should be recommended to adolescents, or to evaluate whether the installation of filtering software will have a detrimental impact on accessibility of health information [13]. Because many of the search behaviors modeled by these simulations are similar for both adolescents and adults, results from studies that simulated one or the other group likely apply to both groups.

The results of this study suggest that such simulations can focus on the use of search engines, but that very-broad search terms and, especially for adolescents, common spelling errors should be considered. Ads and other nonresult links can be ignored. Since more than 80% of the links that were followed appeared in the top 10 results, and more than 95% were among the top 40, a search simulation need not consider result links beyond these.

### Providers of Internet Health Content

Given the patterns of adolescent searching behavior found in this study, providers of health content can do several things to increase the probability that adolescents will find their sites. Since adolescents rely primarily on the first few results from search engines and do not tend to look at ads, it is important to ensure that health sites appear near the top of the results for searches on health terms. Choices of keywords in the domain name, page title, meta tags, and the first few sentences, as well as links from other sites, can all affect placement in search results. It may also be useful to include some common misspellings in meta-tag keywords and in the body of the text in order to make a site appear in the results page of searches using those misspellings of related search terms. Because most major English-language search engines no longer use the keyword feature of meta tags, site designers are left with the difficult task of working misspelled words (eg, misspelt) into the text without coming across as poor spellers themselves. It is also important that the site descriptions displayed in search engines be attractive to adolescent searchers: while our study did not analyze the various reasons that adolescents chose to follow one link over another, we did observe that they made choices based upon the link descriptions and did not simply select the first link offered. Books and articles, software, and consulting services are all widely available to improve search engine placement and to influence the short summary text that search engines extract for display in search results [28,29]. Organizations that invest large amounts of money in developing sophisticated health-information sites would do well to spend a little bit more to ensure these sites are easily found.

Another area that Internet content providers should focus on is within-site navigation. Because students tend to skip around from place to place within a page and read little in sequence, it is important that sites with a significant adolescent audience are well organized, concise, and understandable. Long paragraphs, too many links, and difficult vocabulary all decrease the likelihood of adolescents finding health information they are seeking, even if it is contained within a site. Internet content producers should attempt to understand the needs of the site visitors and build hierarchal structures that reflect those needs. For example, if one of the primary needs of individuals visiting the Alcoholics Anonymous site is to find a local meeting, the first page of the site should include an obvious link (eg, "Find an AA Meeting Near You") that leads to another page that returns the nearest meetings after entering in a zip code or city name. While ease of within-site navigation is important for all visitors to health information sites, some information providers may want to develop sites targeted specifically to adolescents. While they might like the targeted information once they found it, we observed that adolescents tend to rely on general-purpose search engines. Thus, developing special youth-targeted versions of information sites may be of somewhat limited utility, unless also accompanied by advertising or education campaigns that make adolescents more likely to find such sites.

Rather than changing Web sites or their presentation in search engines, it may also be useful to undertake education campaigns to improve the search strategies and tactics that adolescents use when seeking health information. It may be helpful to guide them towards youth-oriented directories or search engines, rather than general-purpose search engines. For example, both Yahoo! and Google offer directories with subcategories of sites designed for teens that cover various health topics. This approach may be facilitated by including links to such resources on the Web browser's starting page in schools and libraries. Alternatively, adolescents might be taught techniques for formulating and refining search terms at general-purpose search engines, adding or dropping more-specific words based on the kinds of results returned. They might also be taught to notice potential search term misspellings based on surprising search results. Finally, adolescents might also be taught techniques for systematically exploring within a Web site to find the kind of information they are looking for.

## Limitations and Future Research

There are several important limitations to the interpretation of these results.

First, this was not a representative or random sample of adolescents. It was a small convenience sample with a selection bias toward adolescents with strong Internet searching skills. While the results cannot be generalized to all adolescents and do not capture the full range of adolescent searching experience, we can assume that the average adolescent would have had even more trouble than our study participants in finding health information on the Internet.

Second, the health-related search questions were deliberately constructed to avoid controversial topics such as safe sex, abortion, and homosexuality. Given that adolescents are often faced with health problems related to sexuality, their actual search behavior and success at finding health information related to sexuality may not be reflected in our results. Another concern is that participants may have changed their search behavior because of the presence of observers and because they were aware that their search behaviors were being recorded. For example, students who had trouble finding an answer may have persisted in their search longer than they would have in a nonresearch setting. Alternatively, because students knew they had several search questions to answer during a single class period, they may not have been as persistent as they might have been with a more personally-relevant question and less-restricted search time. Thus, the data here reflect a rough estimate of persistence for an adolescent looking for health-related information. Also, searching was conducted individually, while in practice many searches both at home and at school are conducted with friends, teachers, or family close by. While it is difficult to know how this would affect searching behavior without future research, it is possible that students would act differently (eg, receive help with spelling).

Finally, while components of our classification scheme for successful versus unsuccessful searching have been previously validated, the overall scheme was modified to more accurately code the search results as correct, complete, and useful. A more-systematic validation of coding schemes for health information search results is an important area for future research.

More research is needed to validate the results presented in this article, as well as determine if results vary for different populations (eg, age, race, and experience with health searching) and different health questions (eg, finding a practitioner versus finding the answer to a question). Additionally, instead of focusing on how adolescents currently search for health information, future studies may also want to explore interventions aimed at improving their searches. For example, should health portal sites designed for adolescents or online directories be used? Or would the current practice of using common search engines, but with adolescents learning improved search tactics be more effective? Also, which search strategies lead to sites that are the most likely to be accurate and influence adolescents to change their behavior?

## Conclusions

This study provides a useful snapshot of current adolescent searching patterns. The results have implications for constructing realistic simulations of search behavior, and for both information providers and educators. Analyzing search behavior through actual observation should be a cornerstone in any effort to improve adolescents' access to health information.

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## Conflicts of Interest

None declared.

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Original Paper

# How do Consumers Search for and Appraise Information on Medicines on the Internet? A Qualitative Study Using Focus Groups

Geraldine Peterson[1], BPharm; Parisa Aslani[1], BPharm, PhD, Grad Cert Ed Stud (Higher Ed); Kylie A Williams[1], DipHPharm, PhD

Faculty of Pharmacy, The University of Sydney, Australia

**Corresponding Author:**
Geraldine Peterson, BPharm
Faculty of Pharmacy
Pharmacy Building A15
The University of Sydney
NSW 2006
Australia
Phone: +61 2 9351 4445
Fax: +61 2 9351 4391
Email: g.peterson@pharm.usyd.edu.au

## Abstract

**Background:** Many consumers use the Internet to find information about their medicines. It is widely acknowledged that health information on the Internet is of variable quality and therefore the search and appraisal skills of consumers are important for selecting and assessing this information. The way consumers choose and evaluate information on medicines on the Internet is important because it has been shown that written information on medicines can influence consumer attitudes to and use of medicines.

**Objective:** To explore consumer experiences in searching for and appraising Internet-based information on medicines.

**Methods:** Six focus groups (N = 46 participants) were conducted in metropolitan Sydney, Australia from March to May 2003 with consumers who had used the Internet for information on medicines. Verbatim transcripts of the group discussions were analyzed using a grounded theory approach.

**Results:** All participants reported using a search engine to find information on medicines. Choice of search engine was determined by factors such as the workplace or educational environments, or suggestions by family or friends. Some participants found information solely by typing the medicine name (drug or brand name) into the search engine, while others searched using broader terms. Search skills ranged widely from more-advanced (using quotation marks and phrases) to less-than-optimal (such as typing in questions and full sentences). Many participants selected information from the first page of search results by looking for keywords and descriptions in the search results, and by looking for the source of the information as apparent in the URL. Opinions on credible sources of information on medicines varied with some participants regarding information by pharmaceutical companies as the "official" information on a medicine, and others preferring what they considered to be impartial sources such as governments, organizations, and educational institutions. It was clear that although most participants were skeptical of trusting information on the Internet, they had not paid conscious attention to how they selected information on medicines. Despite this, it was evident that participants viewed the Internet as an important source for information on medicines.

**Conclusions:** The results showed that there was a range of search and appraisal skills among participants, with many reporting a limited awareness of how they found and evaluated Internet-based information on medicines. Poor interpretation of written information on medicines has been shown to lead to anxiety and poor compliance to therapy. This issue is more important for Internet-based information since it is not subject to quality control and standardization as is written information on medicines. Therefore, there is a need for promoting consumer search and appraisal skills when using this information. Educating consumers in how to find and interpret Internet-based information on medicines may help them use their medicines in a safer and more-effective way.

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**KEYWORDS**

Medicines; drugs; information; Internet; consumers; focus groups; qualitative research

## Introduction

Consumers frequently use the Internet as an information source and it has been reported that 80% of adult Internet-users have accessed it for general health information [1]. More specifically, 36% of Internet-using consumers have used the Internet as a source of information on medicines [1].

It is broadly acknowledged that health information on the Internet is of variable quality as evidenced by the large number of studies that have explored the quality of consumer health information on the Internet [2]. This is to be expected because the Internet is a free medium. It has also been widely postulated that consumers searching for health information are in danger of being harmed by poor-quality information even though there is little evidence of this [3]. A consumer's risk for encountering poor-quality health information is purportedly related to the proportion of poor-quality information on the Internet and the consumer's ability to filter out this information [2]. As the quality of information on the Internet cannot be controlled, the more-imperative issue is the ability of consumers to search through information and assess its quality so they are able to avoid untrustworthy information [4]. An Australian study suggested that consumers found it difficult to describe how they distinguished good-quality information on medicines from poor-quality information on medicines on the Internet [5]. However, this study was limited by a small (N = 9), select sample and did not explore in-depth the way consumers searched for and selected information on medicines.

There is little information concerning consumer Internet-search behavior for health information. One study reported that participants mainly select Web sites that looked and read professionally and preferred understandable Web sites from official sources that used scientific references [6]. When participants were observed while searching for health information on the Internet, it was found that they mainly used search engines and were described as having "suboptimal" search skills [6]. This study reported that participants did not find blatantly-incorrect health information in their searches [6]. This indicates that they had used selection criteria to decide on the Web sites, though the criteria were not fully described in this paper.

Consumer use of information on medicines is an important issue because written information on medicines has been shown to influence consumer attitudes towards their medicines, and affect their medicine-taking behavior [7]. Furthermore, medicines, unlike general health issues, have overtly-commercial imperatives, which may influence the information available. Since the Internet has become a common source of information on medicines, it is important to identify the way consumers are using it. Therefore the aim of this study was to explore consumer use of Internet-based information on medicines. In particular, the objectives were to:

- examine consumer attitudes to the availability and quality of Internet-based information on medicines;
- explore consumer reasons for using this information;
- explore consumer experiences in searching for and appraising information on medicines;
- investigate the self-reported impact and application of this information.

This paper will present results from the broader study on consumer experiences in searching for and appraising Internet-based information on medicines.

## Methods

### Selection of Method

Focus groups were selected to address the study aims because they are useful for time-efficient, in-depth exploration of issues surrounding topics where there is little information [8- 10]. Since there is little known about how consumers use Internet-based information on medicines, focus groups were an ideal method for exploring this issue. The results of focus groups are not intended to be statistically generalizable, but are used to reveal the range of consumer opinions and attitudes.

### Research Instrument

An interview guide consisting of general themes constructed from the literature was prepared (Table 1). This paper focuses on results ensuing from the exploration of themes 4, 5, and 6. The interview guide was composed of open-ended questions that addressed various issues pertaining to consumer use of Internet-based information on medicines; the questioning route was designed to stimulate discussion [11- 13].

**Table 1.** Themes for focus group interview guide*

1. General opinions about the Internet as a source of information on medicines.
2. Experiences in using the Internet to seek information on medicines.
3. Reasons for seeking information on medicines.
4. The methods and process of searching for information on medicines.
5. Opinions and critique of the information found.
6. Experiences in the evaluation of the quality of Internet-based information on medicines.
7. Feelings after reading the information.
8. Actions taken as a result of reading the information.
9. Perceived benefits and drawbacks of the Internet as a source of information on medicines

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[*] This paper focuses on results ensuing from the exploration of themes 4, 5, and 6.

The interview guide and questioning route was pretested with a convenience sample of consumers (N = 13) to test for interpretation, appropriateness, and comprehensiveness, and to establish face and content validity. No significant changes were made to the interview guide or questioning route as a consequence of this pretest.

### Participant Recruitment

After approval was granted by the Human Research Ethics Committee of The University of Sydney, participants were enlisted for the focus groups by a recruitment agency. Participants were recruited from the agency's database of consumers across metropolitan Sydney, Australia via telephone using a screening questionnaire.

Consumers were deemed to be eligible for this study if they had sought Internet-based information on medicines in the preceding 12 months. This bounded reference period was applied to allow for a suitable recall of past events [14] while also allowing enough time for consumers to have used the Internet for this purpose. Inclusion criteria required that participants were 18 years of age or over, did not require a translator to take part in focus group discussions, did not have training as a health professional, and did not have specialist Internet training. Participants were financially reimbursed for their time and travel expenses.

### Study Design

Six focus groups were conducted in a number of locations around metropolitan Sydney in March to May 2003.

To approximate a representative cross section of consumers, participants were recruited with the intention of including subjects from both genders and across different age groups. Focus groups were age stratified to achieve a level of homogeneity within each group. The use of stratification may increase congruency between participants, thereby allowing a more comfortable discussion [11,15]. Eight persons were recruited for each focus group to ensure that groups were large enough to motivate a discussion, yet small enough allow for all opinions to be heard [11]. The number of groups needed was not determined beforehand because data was collected until saturation occurred (the point where no new themes emerged) [10]. In this study, saturation occurred by the sixth focus group.

The focus groups were facilitated by a skilled moderator while 2 assistant moderators observed and took notes. The group discussions were 1 to 1.5 hours in duration and were digitally sound recorded after permission was obtained from all participants. The recordings were transcribed verbatim. Participants also completed a demographics questionnaire that collected data on Internet usage.

### Data Analysis

The verbatim transcripts were entered into NVivo qualitative software [16] and thematically content analyzed using a grounded theory approach. The grounded theory approach is an inductive approach to analyzing qualitative data, where ideas and emerging themes are systematically coded to generate theory [17].

## Results

This paper presents participants' responses to themes 4, 5, and 6 (Table 1). Responses to other themes are currently unpublished.

### Demographics

Forty-six consumers participated in this study. The age of the participants ranged from 18 to 67 years, with a median of 41 years (interquartile range, 21 years) and a mean of 41.7 years (standard deviation, 12.7 years). Fifty-seven percent of the participants were female. The majority of the participants were employed full-time (58.7%) and about a fifth were either retired or full-time homemakers. Almost half the sample (47.8%) had occupations that could be classified as managers, professionals, or associate professionals [18]. A high proportion of the sample (65.2%) had completed further educational qualifications beyond high school, and 23.9% of the sample had a bachelors or postgraduate degree.

Data on participant usage of the Internet is presented in Table 2. The majority of participants had a few years experience in using the Internet and over half had accessed it from both their home and workplace. In addition to using the Internet for information on medicines, most participants also used it for general health information and for services such as e-mail.

Data on participant usage of the Internet for information on medicines is presented in Table 3. In addition to using the Internet, many participants also reported using other media such as magazines for information on medicines. This variety of information sources has also been seen in another Australian study on consumer use of Internet-based general health information [19]. Even though most participants (82.6%) were seeking information for themselves, many reported also searching for other family members. This was also reflected in the aforementioned Australian study that showed that 63% of Internet-using consumers sought health information mainly for themselves [19].

**Table 3.** Participant usage of the Internet for information on medicines (N = 46 participants)

| Characteristic | Usage | Frequency, Number of Participants | Relative Frequency, (% of Participants) |
|---|---|---|---|
| Media sources of information on medicines (more than one category could be selected) | Internet | 46 | 100.0 |
| | Magazines | 31 | 67.4 |
| | Television | 23 | 50.0 |
| | Books | 22 | 47.8 |
| | Radio | 9 | 19.6 |
| Person that Internet medicine information was used for (more than one category could be selected) | Self | 38 | 82.6 |
| | Spouse/partner | 24 | 52.2 |
| | Child | 19 | 41.3 |
| | Parent | 17 | 37.0 |
| | Another relative | 13 | 28.3 |
| | Friend | 6 | 13.0 |
| Health categories for which information on medicines had been sought for (more than one category could be selected) | Allergies | 20 | 43.5 |
| | Arthritis/joint pain | 14 | 30.4 |
| | Asthma | 14 | 30.4 |
| | Cancer | 13 | 28.3 |
| | Skin disorders | 12 | 26.1 |
| | Hormones | 11 | 23.9 |
| | Other miscellaneous | 11 | 23.9 |
| | Child health | 10 | 21.7 |
| | Diabetes | 10 | 21.7 |
| | High cholesterol | 9 | 19.6 |
| | Immunization | 9 | 19.6 |
| | Pain and injury | 9 | 19.6 |
| | High blood pressure | 8 | 17.4 |
| | Mental health | 8 | 17.4 |
| | Digestion/stomach disorders | 6 | 13.0 |
| | Infections | 6 | 13.0 |
| | Migraine | 6 | 13.0 |
| | Osteoporosis | 6 | 13.0 |
| | Alzheimer's disease | 5 | 10.9 |
| | Dementia | 5 | 10.9 |

**Table 2.** Participant usage of the Internet (N = 46 participants)

| Characteristic | Usage | Frequency, Number of Participants | Relative Frequency, % of Participants |
|---|---|---|---|
| Length of experience in the use of the Internet | More than 5 years | 17 | 37.0 |
| | 4 to less than 5 years | 13 | 28.3 |
| | 3 to less than 4 years | 7 | 15.2 |
| | 2 to less than 3 years | 4 | 8.7 |
| | 1 to less than 2 years | 4 | 8.7 |
| | Less than 1 year | 1 | 2.2 |
| Location of Internet access | Home and work | 25 | 54.3 |
| | Home only | 16 | 34.8 |
| | Work only | 5 | 10.9 |
| Activities that the Internet is used for<br>(more than one category could be selected) | Information on medicines | 46 | 100.0 |
| | E-mail | 45 | 97.8 |
| | Health information | 43 | 93.5 |
| | Travel information/booking | 40 | 87.0 |
| | Banking/financial services | 36 | 78.3 |
| | News, weather, sport | 34 | 73.9 |
| | Job or study related research | 34 | 73.9 |
| | Real estate | 33 | 71.7 |
| | Shopping—product research | 33 | 71.7 |
| | Games and hobbies | 26 | 56.5 |
| | Chat or instant messaging | 22 | 47.8 |
| | Shopping—purchasing | 19 | 41.3 |
| | Purchasing medicines | 7 | 15.2 |

## Searching for Internet-Based Information on Medicines

### Search Engines

All participants had used a search engine to find information on medicines. Most participants had a single favorite search engine that they would always use, but a few reported using more than one search engine to find the information they required.

The choice of search engines was determined by many different factors ranging from the default search engine on their browser to active selection based on self-developed criteria. Numerous participants were influenced by the search engine that was used by coworkers, for example:

> *I saw it on this guy's computer and . . . I thought 'Oh, I'm going to use this'. That's how I started it at work.* [Group 4, Participant 8]

Some participants also reported that their browser automatically defaulted to a certain search engine and a few participants were unable to identify the search engine they used, for example:

> *Couldn't tell you [the search engine] really. I just log on and use whatever comes on.* [Group 3, Participant 6]

Many participants used search engines recommended by family and friends.

There were certain determinants that led some participants to actively choose a specific search engine. These included perceptions of the credibility of the search engine, ease of use, relation with services such as e-mail, and a lack of advertising. These determinants did not necessarily include perceived quality of the information on medicines obtained through their use.

A few participants reported using AltaVista [20] because they thought it had an educational advantage, for example:

> *It's got an educational edge, that's my experience. When I was at university doing my second degree, that was one that was sort of promoted as credible I suppose.* [Group 1, Participant 1]

Some participants preferred to use Ask Jeeves [21] because they could enter the searches in a question or statement format rather than using search terms.

Many participants reported using Yahoo! [22] because it appeared as a default homepage, was used as a personal e-mail account, or was advertised through other media. Yahoo! and Google [23] were also said to be useful for Australian-only searches.

Google was undoubtedly the search engine the majority of participants used most and preferred. This was especially true of the younger participants. The common perception was that Google appeared to be straightforward and did not focus on advertising, for example:

> *It's just got less [rubbish]. It seems to be direct to what you want. I think that other [search engines] always have these categories and they always have suggestions for buying things and stuff like that but*

> *Google's pretty much straight to the point. It's simple.* [Group 4, Participant 6]

Participants also commented that this search engine was useful for suggesting spelling corrections when errors were made, as medicine names were sometimes difficult to spell. A few participants reported preferring Google as their search engine of choice specifically for health-related searches but were unable to explain reasons for their preference.

Other search engines used by participants were metasearch engine Dogpile [24], Australian metasearch engine Search66 [25], Australian-based search engine Web Wombat [26], and ninemsn [27], the Australian-based access to search engine MSN Search [28]. Many participants who used metasearch engines were unaware of the difference between these and normal search engines.

Generally, although a variety of search engines were used by participants when seeking information on medicines, the majority of participants used the same few dominant search engines. Participants generally preferred search engines with less advertising, and would continue to use the same search engine if they were successful in their searches. Most participants used the same search engine that they used for nonhealth information, and were usually influenced by what was used by friends, family, and colleagues.

### Search Processes

Participants displayed a large variation in the process of searching for information on medicines.

Most participants found information by typing the name of the medicine (drug name or brand name) into the search engine. A few participants felt this was the only way of finding information on a medicine, for example:

> *How do you put in your searches?* [Interviewer]
>
> *Medicines are really specific to just the name.* [Group 6, Participant 2]

Other participants reported looking for broader information, for example:

> *I often use a more general [search]. I might use something like 'women's health' or something. And I like to see a whole range of things . . . rather than targeting specifically . . . and then I choose within that.* [Group 1, Participant 2]

The information found through this type of search was said to be less specific to one medicine and had more general or comparative information.

Some participants used more-advanced search techniques such as quotation marks, phrases, and extra words to narrow down their searches. They displayed an understanding of how these techniques helped to focus their searches, for example:

> *If you type it in with quotation marks, it'll search for those words together whereas if you type them separately, it'll just search for them anywhere.* [Group 4, Participant 6]

Participants reporting advanced skills were generally observed to be those who were younger or those who had greater experience of the Internet through work or study.

However, it was clear that search skills varied significantly. The following interchange illustrates the mixed levels of understanding as to how search engines work:

> *[You need to] ask a specific question . . . 'What are the side effects?' rather than typing in 'penicillin'.* [Group 5, Participant 4]
>
> *Yeah, you really have to do a whole sentence. A whole statement.* [Participant 6]
>
> *I would type in 'penicillin side effects'.* [Participant 3]
>
> *'Then it could hit on 'penicillin' or it could hit on 'side effects'.* [Participant 4]

The uninformed way in which some participants agreed upon what they considered to be optimal search skills was obvious in the group discussions. The majority of participants in this study who reported searching using less-than-optimal techniques—such as typing in whole questions—tended to be nonworkers, for example, full-time homemakers or retirees.

The search skills of participants varied widely and these differences may affect the resulting information that participants encounter. Searching via a search engine however, was not the only way of finding information on the Internet on medicines.

### Other Methods of Finding Internet-Based Information on Medicines

Some participants mentioned ways of finding information on medicines in addition to using search engines.

A few participants said that they guessed the Web sites of medicines by typing the name of the medicine in the address bar in the format of www.[brand name or drug name].com.

Several participants found information on medicines from Web sites recommended by family and friends, and from seeing advertisements in seniors' and health publications. Some reported bookmarking favorite Web sites for future reference and a few subscribed to mailing lists at health-related Web sites.

One participant described searching for information on medicines using online journals. Although aware that the information was not aimed at consumers, this participant still chose to use this means to search for pertinent information on medicines:

> *I actually searched via . . . the professional journals . . . And I guess that was a little bit harder to do it that way because . . . reading through the journals was quite difficult. I tend to just go to the abstracts.* [Group 2, Participant 2]

Participants reported using a variety of search skills to obtain information on medicines. However, the important issue was how they selected and appraised the information.

## Appraising Internet-Based Information on Medicines

### *Selecting Internet-based Information on Medicines*

Participants described different ways of choosing which Web site to visit when selecting from the numerous results obtained from using a search engine. Some worked down the list of results from the first one while others looked for keywords in the Web site descriptions or for the Web site's recency. Often participants made a judgment based on the URL (Web page address) of the result, for example:

> *I actually like looking at the actual web address, just seeing how professional it is. Like if it's some silly thing, I won't bother going into it.* [Group 4, Participant 1]

Many participants also reported looking for indicators in the Web site address to determine whether it belonged to a government, a university, an official organization, or a pharmaceutical company.

Even though most participants said they would not go beyond the first page of the search results, one expressed the opinion that the best information was in the middle of the results and not on the first few pages. This participant had the erroneous opinion that the first pages of results are older and that results appeared mainly in the order in which the information had been created.

Many participants reported looking for the country of origin of the information and preferred information generated from their country of residence, for example:

> *If I'm searching for a medication . . . and it brought up some things and I noticed it was in Australia, I click on that.* [Group 4, Participant 2]

These participants felt that Australian information would be more applicable to them and professed an awareness of health-setting issues such as differences in the brand names and availability of medicines in different countries. However, others had more confidence in United States-based information because they believed that this was where most new research was undertaken.

It was clear that most participants did not pay conscious attention to how they selected Internet-based information on medicines, with one referring to the process as "a vibe" that you obtain through experience. Another described this as a feeling that "things have a look of credibility." Similarly, many participants had trouble in articulating their selection process, for example:

> *I find that sometimes I get to a site and I think 'Gee, this is a good site, but I don't know how I got there.' You know what I mean? You fluke it.* [Group 5, Participant 3]

Despite the inability of many participants to express how they selected information on medicines, many were able to express what they would not select. Participants reported quickly rejecting sites that were slow to load, sites that contained too many graphics, and sites that had pop-up advertisements.

The process of selecting information on medicines varied among the participants. It appeared that all participants had their own criteria for selecting and rejecting information which may or may not appear logical to others. Credibility of the source, however, appeared to be a common determinant in the criteria of all participants.

### *Credibility of the Source of Internet-Based Information on Medicines*

Participants expressed conflicting opinions about the credibility of the source of Internet-based information on medicines. Many participants regarded information produced by pharmaceutical companies to be the "official" information on a medicine and therefore trusted this the most, while many others were suspicious of a possible information bias, for example:

> *If you're looking at [a pharmaceutical company website], they've got factories throughout the world, they're a pretty good company so . . . you know that they've done so much research it's credible information.* [Group 1, Participant 7]
>
> *If it's a pharmaceutical company, they're gonna put a good stance on their drug.* [Group 1, Participant 6]

Many other participants preferred information that originated from what they considered to be impartial and reputable sources such as government, professional, or disease-focused organizations, or university Web sites. A few participants also reported looking for credentials such as the author's qualifications when assessing the credibility of the information provider.

A small number of participants preferred information written by other consumers who had personal experiences in taking the medicine. However, most participants expressed that they would be less likely to trust information on medicines generated by other consumers, for example:

> *There are chat rooms . . . if you've ever been prescribed such and such a medication; you'll get people from all around the world . . .* [Group 1, Participant 6]
>
> *Do you not find that a bit dangerous because everything is rather specific to each person's body?* [Participant 2]
>
> *Oh yeah, but it would be comparable to having a chat with some of your friends.* [Participant 6]

Some participants felt that the authorship of Internet-based information on medicines should be regulated and feared the reliability of the information because there was "no watchdog" for the information published on the Internet while others regarded it as analogous to the way they would trust information given in common conversation and therefore felt comfortable using information in this context.

The credibility of the source of information on medicines was a strong determinant in the selection process. However, in addition to the source participants evaluated information using criteria described in the next section.

### *Evaluating Internet-Based Information on Medicines*

Participants evaluated information on medicines using criteria such as the motive for the information, the language used, and the applicability to their needs.

Almost all participants were skeptical to some degree of Internet-based information on medicines. Many participants professed a universal need for consumers to inherently distrust this information, and to interpret it accordingly. One participant stated that it is important to also consider why the information is on the Internet:

> *What are the motives? Are they conflicting, credible? Whoever has posted it, are they trying to make a profit?* [Group 1, Participant 6]

Other participants described the obviously difficult-to-believe nature of some of this information and looked for signs of conspiratorial or misleading language when deciding whether to trust the information, for example:

> *If it says 'hazard free' and 'completely no side effects', for example, I'm more likely to disbelieve than believe that* [Group 2, Participant 8]

In addition to this awareness of unreliable information on medicines, many participants also expressed an understanding that the information they find may not necessarily be applicable to them and that the information should not be used at face value, for example:

> *The thing with medicines is there's no sort of right or wrong . . . Everyone's different, everyone's going to have a different reaction.* [Group 2, Participant 7]
>
> *When you ask the doctor, they tell you 'well, [the side effects] happen but it's not like that', I think what happens is that the information is not tailored for myself. It's general information.* [Group 2, Participant 6]

Pertinent to this appraisal was the information-filtering process described by participants:

> *It's always better to try and take as much information and try and sift out what's useless* [Group 2, Participant 4]
>
> *When they're talking about people using this medicine, 'ninety-eight percent will die within five years' . . . you have to take that and filter it through a whole bunch of other variables . . . and whether [the information] is not terribly well informed or completely informed.* [Group 1, Participant 6]

One common way in which some participants were able to filter information on medicines was to use other Web sites for comparison and cross-checking, for example:

> *I always go to two or three sites.* [Group 4, Participant 1]

Although participants reported methods of evaluating information, many expressed a difficulty in their evaluation, for example:

> *How do you [figure] out what's useful?* [Group 2, Participant 4]
>
> *How do you know what's reliable and what's not?* [Group 3, Participant 7]

Ultimately, despite an awareness of the shortcomings and difficulties in evaluating the quality of information on medicines, all participants saw the Internet as an important resource for this information, for example:

> *I think as patients you expect immediate information and the Internet, whether it's credible or not, it's the fact that people can get it.* [Group 1, Participant 1]

## Discussion

The issue of consumer use of Internet-based information on medicines is important because it has been shown that written information on medicines can be interpreted by consumers in ways that may lead to anxiety or apprehension [7,29- 32], and a refusal of prescribed medicines [33]. Conversely, it has been shown that written medicine information increases consumer knowledge about their medicines [29,34- 36] and that well-informed consumers with an increased understanding of the purpose of their medicines may have improved compliance and satisfaction with their therapy [29,31,37- 40].

However, studies on consumer use of written information on medicines have evaluated standardized information on medicines such as that produced by pharmaceutical companies, government or professional bodies, or health care practitioners [7]. In contrast, this study explored Internet-based information, which is neither standardized nor subject to universal quality control. Furthermore, medicines in particular are subject to commercial considerations that may have an impact on the motives for and quality of information. Therefore, the impact of Internet-based information on consumer use of medicines may differ from that reported from consumer use of standardized written information on medicines.

The reported search skills of these participants were comparable to those of participants observed while searching for general health information [6] in that they mainly searched using simple strategies in a search engine and chose results primarily from the first page of search results. Although this similarity is not surprising, it does illustrate the overlap between appraising general health information and specifically medicines-related information. Indeed, it was not always possible for consumers in this study to speak on issues surrounding searching for and appraising information on medicines without speaking about other health-related issues.

Participants in this study searched for information on medicines using a range of search techniques from simple 1-word searches and advanced techniques to suboptimal techniques. However, although some participants had little understanding of how search engines worked and possessed suboptimal search skills, a few participants described proficient search skills. Contrary to findings where consumers were observed to use information not applicable to their health setting [6], participants generally reported a strong awareness of the limitations of non-Australian information due to health-setting limitations pertinent to medicines use.

Participants were conscious that there was an abundance of poor-quality information on medicines on the Internet. They were also predominantly aware that information on the use of medicines and on the incidence of side effects is often based on individual factors that should not be seen as applicable to everyone. Therefore, while consumer evaluation skills have been referred to as "meager" [41], the assumption that consumers believe everything they read does not take into account those participants who are savvy about issues such as bias, commercialism, and the lack of regulation of Internet-based information on medicines.

However, the fact that many participants searched for information on a medicine by typing the brand name into a search engine would indicate that it was highly likely that they encountered the Web site of a pharmaceutical company on the first page of results [42], which raises the matter of consumer ability to interpret information on medicines that may not be comparative and unbiased in nature and not aimed at an Australian audience. Even though results from this study would indicate that many participants were aware of these limitations, others still viewed a pharmaceutical company Web site as the official, and therefore exclusive, information on a medicine; this indicates that some consumers may be unaware of or uninterested in information on medicines produced by alternate sources. Nevertheless, it has been suggested that consumers are more likely to search for alternate sources, rather than relying on product brands, as they become more experienced using the Internet [43].

It is clear that there was a variety of skills among participants. Many had not been conscious of some of the issues surrounding the process of searching for and appraising information on medicines and did not undertake this process in the most-constructive way. Furthermore, there have been few studies in the literature that have sought to educate consumers on strategies for effective use of the Internet for health information [44- 47].

### Limitations in This Study

There are several important limitations in this study.

First, as this information is self-reported, consumers may not actually search for and appraise information in the same way as they describe. Such a discrepancy was demonstrated when participants in an observational study were reported to be less likely to look for the sources of the information than was apparent from claims in focus groups [6]. However, participants in that observational study were not searching for information that they would personally use; this may have meant that they were less concerned about the quality of the information.

Second, the bounded period of 12 months in the inclusion criteria may be too long for consumers to correctly remember details of how they searched for and chose information. It might have been beneficial to actually perform a search as an activity to stimulate the participants' memories.

Third, participants in group situations may feel compelled to provide socially-desirable answers that are not necessarily accurate. In this study, we sought to minimize this by informing participants that their results would be confidential and that they were welcome to speak about anything they felt even if they disagreed with someone else. However, this does not negate the problem. Although the use of individual interviews may help to minimize this discrepancy, this method is more time-consuming and cannot use group interaction for the generation of ideas.

Last, certain actions are intuitive and therefore difficult to articulate. Most participants were not able to adequately describe their search and appraisal processes, which suggests that this process may largely be a form of tacit or implied knowledge.

Therefore, future research needs to take into account actual observed (rather than reported) search and appraisal skills of consumers who are seeking information on medicines for their own use.

### Conclusion and Future Research

The results of this study show that consumers may benefit from greater awareness and education on the significance of good search and appraisal skills for information on medicines so that this process is deliberate and conducted with thought rather than being random and tacit. Furthermore, there is evidence that consumers may support education that shows them how to search for information on medicines on the Internet [48]. However, health promotion and education needs to take into account the variety of consumer skills in both searching for and critically evaluating information. Pharmacists are in an ideal position to provide consumer training as they frequently counsel consumers on medicines [49] and have consumers present them with information from the Internet [19]. However, to successfully deliver this program, pharmacists need to be trained in these skills . Furthermore, the impact of pharmacist education on consumers' searches for Internet-based information on medicines and appraisal of that information needs to be evaluated. Therefore, future research by this team will be on the development of a health-promotion program for pharmacists to train consumers to search for and appraise Internet-based information on medicines.

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## Conflicts of Interest

None declared.

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Original Paper

# Design and Testing of a Tool for Evaluating the Quality of Diabetes Consumer-Information Web Sites

Joshua J Seidman[1], PhD; Donald Steinwachs[2], PhD; Haya R Rubin[3], MD, PhD

[1]Center for Information Therapy, Healthwise, Inc, Washington DC, USA

[2]Department of Health Policy and Management, Johns Hopkins University, Bloomberg School of Public Health, Baltimore MD, USA

[3]Departments of Medicine, Epidemiology, and Healthy Policy and Management, Johns Hopkins School of Medicine, Bloomberg School of Public Health, Baltimore MD, USA

**Corresponding Author:**
Joshua J Seidman, PhDExecutive Director
Center for Information Therapy
Healthwise, Inc
600 New Hampshire Avenue NW
Washington DC 20037
USA
Phone: +1 202 945 6810
Fax: +1 202 266 6068
Email: jseidman@healthwise.org

## Abstract

**Background:** Most existing tools for measuring the quality of Internet health information focus almost exclusively on structural criteria or other proxies for quality information rather than evaluating actual accuracy and comprehensiveness.

**Objective:** This research sought to develop a new performance-measurement tool for evaluating the quality of Internet health information, test the validity and reliability of the tool, and assess the variability in diabetes Web site quality.

**Methods:** An objective, systematic tool was developed to evaluate Internet diabetes information based on a quality-of-care measurement framework. The principal investigator developed an abstraction tool and trained an external reviewer on its use. The tool included 7 structural measures and 34 performance measures created by using evidence-based practice guidelines and experts' judgments of accuracy and comprehensiveness.

**Results:** Substantial variation existed in all categories, with overall scores following a normal distribution and ranging from 15% to 95% (mean was 50% and median was 51%). Lin's concordance correlation coefficient to assess agreement between raters produced a rho of 0.761 (Pearson's r of 0.769), suggesting moderate to high agreement. The average agreement between raters for the performance measures was 0.80.

**Conclusions:** Diabetes Web site quality varies widely. Alpha testing of this new tool suggests that it could become a reliable and valid method for evaluating the quality of Internet health sites. Such an instrument could help lay people distinguish between beneficial and misleading information.

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**KEYWORDS**

Internet/standards; information management/standards; medical informatics/standards; guidelines; quality of health care; diabetes

## Introduction

Millions of people around the world are using the Internet each day to find health information, but they do so with little guidance regarding the actual accuracy and comprehensiveness of the information presented on the Web. The development and implementation of a valid method for evaluating the quality of Internet health sites could provide lay people with a tool to identify useful content more easily and to distinguish between beneficial and misleading information. Access to accurate and digestible information has the potential both to empower lay people and to raise the level of dialogue between them and their clinicians, thus enriching the patient-clinician relationship and ultimately improving the quality and efficiency of health care delivery.

This research sought to develop and test a health Web site evaluation model based upon a quality-of-care conceptual framework that evaluates information quality through performance measures, as well as structural measures that are proxies for information quality. The development of the conceptual framework is described in a previous paper [1]. In addition, this research provides a snapshot of the variability in the quality of diabetes consumer information on the Internet. The greater the variability that exists, the greater the need is for such evaluative tools. Previous research has demonstrated Web site variability in other areas [2] and the issues involved are discussed extensively in this issue of the Journal of Medical Internet Research [1].

## Methods

The methods involved in this research involve several levels. First, we explain the development of the model itself and the criteria used in evaluating health Web sites. Second, we discuss the sampling strategy options that could be used to select the subjects (Web sites) to be evaluated. Finally, we outline how the evaluation of individual Web sites was conducted.

### Proposed Model for Evaluating the Quality of Internet Health Information

For a tool to be systematic and objective, it needs to rely on elements that are valid and measurable. We have arrived at a set of criteria (Table 1) to include in a health-information Web site quality-evaluation tool through the lens of a quality-of-care conceptual framework and principles of qualitative meta-analysis. We examined both existing research available and tools that have been developed by health services researchers, physicians, Web experts, and medical librarians.

Although the set of criteria proposed above does not represent the entire universe of important aspects of health information, it does provide a reasonably-good cross-section of structural criteria and performance measures that can be assessed objectively. As described extensively elsewhere, structural measures address the underlying systems and infrastructure, whereas process measures assess the extent to which health care providers have done the right things. Structural characteristics include those in sections I, II, and III of Table 1: explanation of methods, validity of methods, and currency of information. Comprehensiveness (IV) and accuracy (V) serve as both performance and process measures of information quality in that they address how well the Web site performed in creating accurate and comprehensive (or high-quality) information against a set of criteria that were created based upon review of evidence-based practice guidelines and expert opinion.

There are undoubtedly other aspects of health-information quality and communication that affect quality of care. Certainly, user needs and expectations should be considered when evaluating information quality. Moreover, high-quality information by itself will not produce high-quality care, but it generally is a prerequisite for it.

To create valid measures of comprehensiveness and accuracy, we ideally would have compared the information available on Web sites to some gold standard, but no generic gold standard exists for overall health information. Therefore, the model focuses on one specific disease—diabetes—for which a reasonable gold standard exists, the American Diabetes Association's (ADA's) Clinical Practice Recommendations [3].

The Diabetes Quality Improvement Project (DQIP) [4] performance-measurement experience provides a useful model for developing and applying diabetes Web site information-quality performance measures, particularly with respect to content validity, a combination of face validity (or expert validity) and sampling validity. We initially extracted 20 elements to evaluate comprehensiveness and 10 specific criteria that relate to accuracy from the ADA's largely evidence-based practice guidelines. The comprehensiveness criteria reflected the breadth of content covered in the ADA guidelines, an important aspect of sampling validity. The ADA determined the coverage of topics based upon their expert panels' assessment of the clinical evidence. We added these 30 measures to a set of structural characteristics that were extracted from the existing tools and from suggested evaluation criteria in the literature. We wrote a definition for each item in the tool in order to precisely specify what would constitute a positive score on each criterion.

The next stage of measure development involved a review of measures by relevant experts for the purpose of strengthening the instrument's face validity. We sought feedback from 3 experts in diabetes performance measurement, all of whom served on the Diabetes Quality Improvement Project technical-expert panel (Barbara Fleming, MD, PhD; Sheldon Greenfield, MD; and Richard Kahn, PhD). Comments focused primarily on the comprehensiveness and accuracy sections, and can be grouped into 2 categories.

First, the experts believed that the set of comprehensiveness criteria was inadequate if it was to ensure that all major areas of diabetes care were addressed. Specifically, they suggested inclusion of 4 additional criteria in the comprehensiveness set (prevention, psychological aspects, neuropathy, and obesity), all of which were added to the tool, further strengthening the content validity of the tool. The experts were satisfied with the accuracy's section representative selection of items from the broader comprehensiveness set.

Second, one of the experts raised concerns about the feasibility of measuring accuracy based upon the measures' proposed definitions. That concern was addressed in 3 ways. First, the technical definitions for the accuracy measures received further refinement. Second, a reviewer-training session was added to improve the likelihood that the tool would be used according to objective criteria. Finally, actual testing of the proposed measures was conducted, just as it had been done prior to the approval of Diabetes Quality Improvement Project's performance measures.

In the reviewer-training session, we described each measure and technical definition to the 2 other reviewers (there were originally 2 external reviewers, but one dropped out later in the evaluation process, prior to reviewing any sites) and then went through a small sample of diabetes sites with the abstraction tool to demonstrate its application. Those initial reviews raised 7 specific questions, 4 of which related to the measure specifications in the accuracy section. These items were clarified and the guidance in Table 2 was provided to clarify the issues for each reviewer during their respective independent reviews. The external reviewer was a physician and a master's-degree candidate at the Johns Hopkins School of Public Health. This tool is designed to be applied by those with some public health background, but not necessarily with clinical experience; future assessment of the tool should examine the minimum skills required for reviewers.

**Table 1.** Proposed measurable criteria for credibility score for diabetes sites

| Category | Measurement | How Measured |
|---|---|---|
| I. Explanation of methods | a. Content generation explanation<br>b. Identification & disclosure | a. Site has explanation of process for generating its health content<br>b. Author(s) listed and affiliations, credentials, and contact information provided |
| II. Validity of methods | a. Referenced material<br>b. Peer review | a. Assertions supported by referenced material<br>b. Material on site has gone through peer review |
| III.<br>Currency of information | a. Updating process<br>b. Content dating<br>c. Timely update | a. Site has explanation of process for updating its health content<br>b. Each Web page indicates date of last update<br>c. Page updated within last 6 months |
| IV.<br>Comprehensiveness of information | a. Screening<br>b. Glycemia tests<br>c. Nutrition<br>d. Exercise<br>e. Acute episodes<br>f. Secondary diabetes<br>g. Foot care<br>h. Dyslipidemia<br>i. Smoking cessation<br>j. Nephropathy<br>k. Retinopathy<br>l. Immunization<br>m. Insulin administration<br>n. Oral medications<br>o. Glucose monitoring<br>p. Care of children<br>q. Gestational diabetes<br>r. DCCT (Diabetes Control & Complications Trial) implications<br>s. UKPDS (United Kingdom Prevention of Diabetes Study) implications<br>t. Insulin/glucose explanation<br>u. Obesity<br>v. Prevention Psychological aspects<br>w. Neuropathy | Each of these aspects (primarily drawn from the clinical practice recommendations of the American Diabetes Association [3]) addressed and discussed on the Web site |
| V.<br>Accuracy of information | a. Type 1 vs Type 2<br>b. Secondary causes<br>c. Diagnostic tests<br>d. HbA1c test<br>e. Albumin tests<br>f. Cholesterol tests<br>g. Warning signs<br>h. Hypoglycemia prevention<br>i. Oral medications<br>j. Rezulin | 1. Explain Type 1 (lack of insulin) and Type 2 (insulin doesn't work effectively)<br>2. Explain main secondary causes: drugs (pentamidine, corticosteroids, thiazides, niacin), pancreatic disease (chronic pancreatitis, hemochromatosis, cystic fibrosis, pancreatic surgery), endocrine disorders (Cushing's disease, acromegaly, pheochromocytoma, thyrotoxicosis), genetic syndromes (lipodystrophies, myotonic dystrophy, ataxia telangiectasia), insulin-receptor syndromes<br>3. Explain diabetic threshold for fasting blood glucose test (> 125 mg/dL) and oral glucose tolerance test (> 199 mg/dL)<br>4. Explain risk associated with HbA1c levels > 8%: impact on risk of coronary artery disease, kidney disease, and retinopathy<br>5. Explain macroalbuminuria test (goal: negative) and microalbuminuria test (goal: < 30 mg/g creatinine)<br>6. Explain HDL/LDL difference and LDL target level (< 100 mg/dL)<br>7. Explain warning signs of acute diabetic episodes (fainting, seizures, state of serious confusion)<br>8. Explain what brings on hypoglycemia (not eating enough/on time, exercise without food/insulin adjustment, weight loss, too much insulin/oral medications)<br>9. Explanation of all 5 classes of oral medications (sulfonylureas, meglitinides, biguanides, glitazones, alpha glucosidase inhibitors)<br>10. Explain liver problems associated with the glitazone Rezulin and why pulled back from market |

**Table 2.** Issues identified in initial sample of diabetes sites during reviewer training*

| Issue | What to Do About It |
|---|---|
| Many sites merely aggregate of miscellaneous information | Can still judge site by overall performance |
| Extent to which sites cover both childhood and adult diabetes | Sites specifically stating their focus on Type 1 diabetes are excluded; all others are included |
| Some structural criteria may be hard to assess, partially because some pages document structural issues well and other pages within the site may not | Judge based on whether the anchor site (main home page) documents structural characteristics, etc |
| Accuracy/Secondary Causes (V.b.) measure: Some sites may address some, but not all, of the causes | Score positive if they include at least 4 of the 5 causes |
| Accuracy/Albumin Tests (V.e.) measure: Some sites may use "proteinuria" instead of "macroalbuminuria" | Either "proteinuria" or "macroalbuminuria" is fine |
| Accuracy/Hypoglycemia (V.h.) measure: Some sites may address some, but not all, of the prevention methods | Score positive if they include at least 3 of the 4 prevention methods |
| Accuracy/Oral Medications (V.i.) measure: Some sites may refer to acarbose rather than the broader drug class name of alpha glucosidase inhibitors | Score positive if either term is used |

* Roman numerals plus letters (V.b., V.e., V.h., and V.i.) refer to Table 1.

## Sampling Strategy

We selected a specific search term (ie, "diabetes") and used the Direct Hit search engine (now subsumed by the Teoma search engine) [5], which claims that it tracks the most "popular" sites by search term. Any sites coming from a duplicate parent were eliminated, as they were covered in the review of the parent site (eg, *www.diabetes.com* would include any pages that include *www.diabetes.com/xxx*). We also developed a standardized set of eligibility criteria. Sites were excluded for 4 reasons. First, sites addressing only Type 1 diabetes or "juvenile diabetes" were excluded because some of the comprehensiveness criteria would not apply to Type 1. Second, a site in which there was a clear explanation that it was not designed for consumers would not be appropriate for an evaluation of consumer health Web sites. Third, sites that only included "news" and were not designed to offer general diabetes content were not evaluated. Finally, sites were excluded if the Web site address led to a dead link.

## Evaluation Process

With the final tool for evaluation of Web site credibility, we began the process of evaluating the sites that met the eligibility criteria through an objective and systematic process.

First, we created a data-abstraction tool, which includes all of the proposed evaluation criteria (listed in Table 1) as well as additional background or "demographic" data on the individual Web sites. This demographic data was used to characterize Web sites, primarily with respect to sponsorship characteristics (advertising vs no advertising, profit vs not-for-profit, academic vs nonacademic, and governmental vs private). The abstraction tool and evaluation-definitions table were accompanied by instructions (originally clarified in a table sent via e-mail to the reviewers) on specific items that arose during the reviewer-training session (which are summarized Table 2).

Second, we created a set of composite scores by section and overall score based upon the evaluation instrument and the data-abstraction tool.

Third, we used the software application "Catch the Web" [6] to "freeze" (download a copy of) Web sites.

Finally, the external reviewer and the principal investigator (JS) scored each site with respect to the attributes in the evaluation model. The Web site received 1 point for each criterion that it met (eg, 1 point if it explains its process for generating health content [I.a., in Table 1], 1 point for conducting a peer-review process [II.b., in Table 1], and so forth). The same held true for the comprehensiveness criteria. For the accuracy criteria, however, the site only was evaluated (and therefore only counted in the denominator) on those aspects that it did address, thus maintaining a distinction between accuracy and comprehensiveness. Otherwise, a site would get penalized twice for not providing information on kidney disease testing, when it really only represents a failure of comprehensiveness or breadth, rather than the provision of inaccurate health information.

## Analysis of the Evaluation Tool

Assessment of the tool involved an evaluation of the tool's feasibility, performance on individual criteria, distribution of scores, and reliability. Feasibility depends on how long it takes to review sites (quantitative) and whether reviewers had trouble applying the instrument (qualitative).

Considerable controversy exists in the literature regarding selection of statistical methods for assessing reliability in the development of new tests, tools, and indexes. Most of this debate relates to measures of clinical evaluation, and no research has addressed this issue for the tool being tested here.

We employed 3 methods to test inter-rater reliability. First, we used the kappa statistic to assess how much agreement existed between reviewers relative to expected agreement by chance on each criterion. The kappa value is influenced substantially by "prevalence" so that rare events are likely to have low kappas even when agreement is high [7]. To address this limitation, a second measure of reliability, Lin's concordance correlation coefficient, was used to measure how close the 2 raters' judgments fall along a 45-degree line from the origin (or a slope of exactly 1.00) [8]. Additional data are presented for Pearson's r, a direct test of correlation. For the reasons described above, Lin's concordance correlation coefficient appears to be the most-appropriate method for evaluating the overall reliability of our index, but it is worthwhile to examine the kappa values of each item in the index—particularly in this alpha-testing phase—to provide future researchers clear targets for index refinement.

# Results

Of the 90 sites selected from November 2001 through January 2002, the external reviewer examined 69 and the principal investigator (JS) reviewed 21, plus both reviewed 30 sites for reliability testing.

## Assessment of the Evaluation Tool

Assessment of the Diabetes Quality of Internet Information (Diabetes QII) tool involves several components: feasibility, score means, distributional properties, reliability, and individual criterion performance.

### *Feasibility*

The mean time required to review each site was 30.26 minutes, including identifying sponsorship characteristics, process measures, and outcome measures. Time to review ranged from 3 to 75 minutes, with a standard deviation of 16.26 minutes. The level of variation reflects the diversity in the quantity of information that needed to be reviewed on each Web site.

Qualitatively, some of the information was difficult to locate, although this was much more problematic for the process measures than the outcome measures. In addition, in some cases, trying to discern sponsorship characteristics was difficult and time-consuming. Since sponsorship is not integral to quality measurement, some time could be saved by dropping this item.

### *Distribution of Scores and Performance Summary*

There was considerable variation in the different scoring sections and wide variation in performance overall, with a mean of 50% and a median of 51%. Appendix 1 presents the 90 sites in order of overall score (and secondarily by outcome score) with scoring section breakdowns. There was also great variability among sites in all categories of scores (see Table 3). Overall scores ranged from 15% to 95%, comprehensiveness scores from 13% to 96%, and performance composite scores (combining accuracy and comprehensiveness) from 14% to 97%. The accuracy composite score and the process measure composite score (the latter being a combination of explanation of methods, validity of methods, and currency of information) each ranged from zero to perfect (0% to 100%).

**Table 3.** Distributions of scores for 5 categories

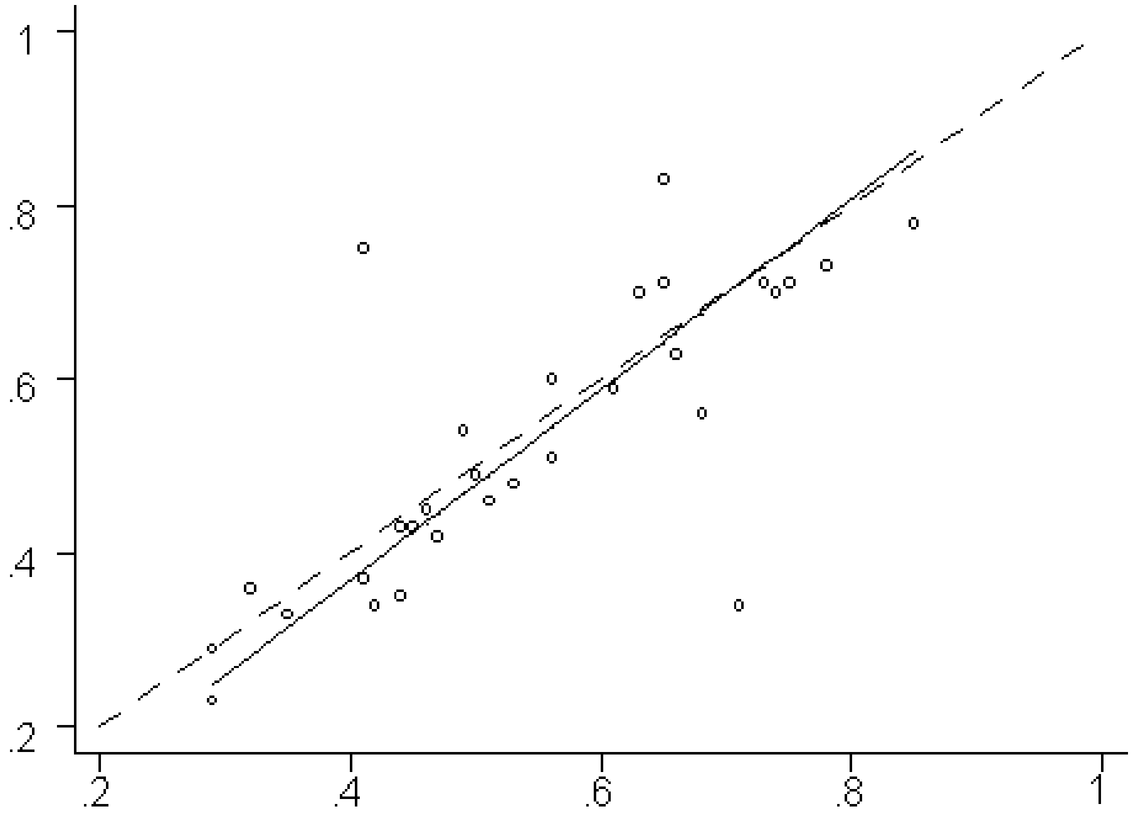
| | Structure Composite | Overall Score | Performance Composite | Comprehensiveness | Accuracy |
|---|---|---|---|---|---|
| Smallest | 0% | 15% | 14% | 13% | 0% |
| 5th percentile | 0% | 23% | 21% | 21% | 0% |
| 10th percentile | 0% | 28% | 31% | 31% | 15% |
| 25th percentile | 0% | 38% | 41% | 46% | 30% |
| Median | 29% | 50% | 55% | 58% | 43% |
| 75th percentile | 57% | 65% | 70% | 75% | 63% |
| 90th percentile | 71% | 75% | 79% | 83% | 78% |
| 95th percentile | 86% | 80% | 82% | 88% | 78% |
| Largest | 100% | 95% | 97% | 96% | 100% |
| Mean | 31% | 51% | 56% | 59% | 44% |
| Interquartile range | 57% | 27% | 29% | 29% | 33% |
| Standard deviation | 28% | 18% | 19% | 20% | 23% |
| Skewness | 0.597 | 0.154 | -0.127 | 0.328 | 0.039 |
| Kurtosis | 2.295 | 2.352 | 2.441 | 2.321 | 2.640 |
| Shapiro-Wilk w test *P* | < .001 | .44 | .65 | .17 | .56 |
| Assessment of normality | Not normal | Normal | Normal | Normal | Normal |

Mean scores were each within 10 percentage points of 50%, except for the structure measure composite score (mean 31%). The mean of the overall score was 51%; of the performance composite, 56%; comprehensiveness, 59%; and accuracy, 44%. The medians were similar to the means: 29%, 50%, 55%, 58%, and 43%, respectively. The interquartile ranges were 57%, 27%, 29%, 29%, and 33%, respectively.

### *Instrument Reliability*

Lin's concordance correlation coefficient produced a rho of 0.761 with a standard error of 0.079. See Figure 1 for a graphical presentation of the data (in which the goal is to have a slope of 1.0 from intercept at 0). The Pearson's r was similar, at 0.769. This set of values suggests moderate to high agreement between raters.

**Figure 1.** Graphical presentation of Lin's concordance correlation coefficient*



* Lin's concordance correlation coefficient:
Data must overlay dashed line for perfect concordance.
Observations = 30, rho = 0.761 (95% CI, 0.607-0.916), standard error (rho) = 0.079, *P*< .001
Pearson's r = 0.769
Slope = 1.094, intercept = -0.069

The kappa statistics for the individual criteria varied substantially, from a low of -0.0465 to a high of 0.7826, with an overall average just under 0.40 (see Appendix 2). Forty-four percent (15 of 34) of the performance composite criteria had kappa values over 0.50 and 68% of them (23 of 34) had values that were statistically significantly different from the expected level of agreement.

A number of the low kappa values occurred in spite of high levels of agreement on those particular items (see "Methods" section for an explanation by Feinstein and Cicchetti [7] regarding why this paradox occurs). For example, the 2 worst kappa values—nutrition/comprehensiveness (-0.0465) and secondary causes/accuracy (0.0000)—had high levels of agreement (90.00% and 96.67%, respectively) but also had exceptionally-high levels of expected agreement because the criterion did not prove to differentiate among sites well.

### *Individual Item Performance*

There was great variation in the scores of individual items, as presented in Table 4, suggesting that different criteria measure different aspects of Web site quality. The median and mean are 51.11% and 51.66%, respectively, and the standard deviation is 25.73%. No items have averages below 5% or above 95%. Although they range from 7.78% to 91.11%, more than 80% of the items average between 15% and 85% (the 10th percentile is 15.56% and the 90th percentile is 85.56%).

**Table 4.** Individual item performance

| Criterion | Percentage of Web Sites Scoring Positively |
|---|---|
| **Process measures average** | 30.63 |
| Content generation explanation | 30.00 |
| Identification and disclosure | 46.67 |
| Referenced material | 34.44 |
| Peer review | 26.67 |
| Updating process | 10.00 |
| Content dating | 51.11 |
| Timely update | 15.56 |
| **Comprehensiveness average** | **59.21** |
| Screening | 38.89 |
| Glycemia tests | 74.44 |
| Exercise | 85.56 |
| Acute episodes | 63.33 |
| Secondary diabetes | 30.00 |
| Foot care | 71.11 |
| Dyslipidemia | 64.44 |
| Smoking cessation | 42.22 |
| Nephropathy | 91.11 |
| Retinopathy | 88.89 |
| Immunization | 7.78 |
| Insulin administration | 64.44 |
| Oral medications | 74.44 |
| Glucose monitoring | 75.56 |
| Care of children | 26.67 |
| Gestational diabetes | 70.00 |
| DCCT (Diabetes Control & Complications Trial) implications | 41.11 |
| UKPDS (United Kingdom Prevention of Diabetes Study) implications | 21.11 |
| Nutrition | 90.00 |
| Insulin/glucose explanation | 71.11 |
| Prevention | 41.11 |
| Psychological aspects | 27.78 |
| Neuropathy | 82.22 |
| Obesity | 77.78 |
| **Accuracy average (of those sites addressing item)** | **48.24** |
| Type 1 vs Type 2 | 78.65 |
| Secondary causes | 22.22 |
| Diagnostic tests | 66.67 |
| HbA1c test | 55.88 |
| Albumin tests | 15.19 |
| Cholesterol tests | 35.59 |
| Warning signs | 87.27 |
| Hypoglycemia prevention | 68.97 |

| Criterion | Percentage of Web Sites Scoring Positively |
|---|---|
| Oral medications | 39.71 |
| Rezulin | 12.22 |
| **Outcome composite average** | **55.98** |
| **Overall average** | **51.66** |

## Discussion

### Great Variability in Quality of Internet Diabetes Information

The wide variation in scores demonstrates that considerable variation exists in the quality of consumer diabetes information on the Internet. In addition, the overall mediocre Web site performance (average score of 50%) suggests that the level of inaccuracy and missing information is substantial. This relatively-low Web site quality suggests that consumers need a way to discern which sites offer high-quality information.

The tool also appears not to suffer from floor or ceiling effects in that there is variation even among "poor" performers as well as room for improvement. There were no overall scores of either 0% or 100% and few that were that close to either end of the spectrum. The fifth percentile was 23% for overall scores and 21% each for the comprehensiveness score and the performance composite. Only 5% of sites received a score of 80% or better on either the overall or outcome composite scores, suggesting room for improvement. One might expect that institutionalization of a Web site information-quality measurement system might lead to longitudinal improvement on scores and reduction in variation, as has been the case with HEDIS (Health Plan Employer Data and Information Set) measurement and health plan performance [9]. For example, the percentage of members in reporting health plans receiving a prescription for beta blockers after a heart attack has steadily increased since the measure was introduced, from a median of 64% in 1996 to 92% in 2000 [10]. If the measures are a valid representation of quality, then one can make the argument that the competitive performance measurement approach has driven system-wide quality improvement.

What is the impact of poor performance? For failed prescription of beta blockers, the evidence suggests that there is no doubt that some people will die due to poor adherence. One could argue that similar risks are involved in the case of inaccurate or misleading Internet health information. According to a January 2002 Pew Internet & American Life Project survey [11], 15 million Americans used the Internet to make a health care decision in the years 2000-2001. As more consumers determine treatment choices based on what they (or their families) read on the Web, the impact of bad information will grow. In the case of diabetes, inaccurate information could mislead a consumer into failing to be aware of all of the signs that an acute diabetic event is beginning. Incomplete information could suggest to the lay person with Type 2 diabetes that limiting carbohydrate intake (to moderate blood sugar levels) is sufficient dietary guidance, when he or she is actually most likely to die from a cardiovascular event, for which fat intake may be equally (or more) important.

The major practical implementation challenge relates to making sure that the tool is generalizable from one condition, diabetes mellitus, to the vast array of medical and health care topics. Nothing from this research demonstrates the quality of Web sites for any condition other than diabetes. In fact, many of the sites—including 3 of the top 5—are diabetes-specific sites, so one would not expect to seek information from them about other diseases. The sample from which to choose for breast cancer, liver disease, or schizophrenia undoubtedly would be much different. However, the intrinsic nature of a tool that addresses performance measures of information quality is that it focuses on a particular condition, especially in the domain of comprehensiveness.

### Validity of the Tool

As discussed earlier, testing the validity of a tool in an area where no other research exists is a considerable challenge. Nevertheless, some aspects of validity have been addressed. Deriving the original measures from the wide range of ADA evidence-based practice guidelines provided some degree of sampling validity. The face validity of the tool was addressed by having the tool reviewed by 3 diabetes performance-measurement experts and then making adjustments to the tool based upon their suggestions. Further refinements of the tool should involve an iterative process with these experts (and additional experts who bring other perspectives, such as diabetes nurse educators and consumers) for 2 reasons. First, the experience of implementation might inform experts' opinions about the value of individual criteria, thus creating an opportunity to combine the quantitative findings with a consensus process to make the tool more efficient and precise. Second, expert input is important to ensure that alterations to the tool based upon quantitative findings do not undermine its face validity. For example, item reduction based upon quantitative aspects of validity could eliminate items so central to the understanding of diabetes information quality that the tool could become less valid.

The tool's ability to differentiate among sites and its lack of floor and ceiling effects offers other suggestions of validity. Further exploration with diabetes measurement experts can be used to ensure that those differences reflect actual distinctions in information quality.

Given that each site evaluation took just over a half hour, the tool does not appear to be particularly burdensome to implement for a single disease. Furthermore, some of that time included the effort to identify each Web site's sponsorship characteristics for the purposes of this research, which would not be part of the evaluation tool itself. In addition, one might anticipate that greater experience with the tool might improve efficiency in the evaluation process. If someone is trying to find an objective, systematic approach to evaluating the quality of diabetes information on the Internet, this is a reasonably efficient and practical solution.

### Tool Reliability and Opportunities for Improvement

The major test of reproducibility, inter-rater reliability, produced good results but also suggested specific opportunities for improvement. The test of concordance (Lin's correlation concordance coefficient) and Pearson's r produced almost identical results: 0.761 and 0.769, respectively. Depending upon which statistician's guidance one chooses to use, this level of agreement could be characterized as "excellent" [12], "good" [13], "substantial" [14- 15], or "moderate" [16].

Setting aside the argument of whether the reliability of the tool tested was moderate, excellent, or somewhere in between, the more-important finding is that the experience of alpha testing this tool has suggested several ways in which reliability could be improved.

First, as the graphical plotting of Lin's concordance correlation coefficient shows in Figure 1, there are 2 clear outliers, which turn out to be Diabetes Education Network (principal investigator, JS, at 75% and external reviewer at 41%) and Diabetes Australia (principal investigator, JS, at 34% and external reviewer at 71%). When the 2 outliers are excluded from the data set, an analysis of the 28 remaining pairs shows a rho of 0.924 and a Pearson's r of 0.932 (a level that suggests excellent rater agreement), a difference of 0.163 on both reliability measurements. A postanalysis discussion between the 2 raters revealed some issues with these 2 sites that could be addressed by refinement of the tool and reviewer training criteria.

In both cases, these sites produce little to no consumer content of their own. They each include many links to other sources—either non-consumer-oriented (eg, Australian diabetes practice guidelines for professionals) or external—some of which were erroneously not captured during the original Web site freezing process. According to the reviewer instructions, Web pages not frozen at the time of abstraction should not be included in that site's evaluation because they may not have been there with precisely the same content at that time. However, it appears that this may not have been adhered to for these 2 sites.

In a dynamic Web site reviewing atmosphere, in which Web site review did not need to be based on the content posted on a site at a specific moment in time, this situation may not have occurred because no freezing software would need to be used. The reviewer instructions—both written and during training—could be made clearer regarding guidance for linked sites. In particular, further clarification could be made regarding the inclusion of links to nonconsumer (professional) content, such as provider practice guidelines.

The second way to improve inter-rater reliability for future versions of the tool relates to the specifics of the reviewer training sessions. Although we conducted a reviewer training session, there is no way to assess if it was thorough enough. Now, with the experience of having done this once, we would add and modify elements of that training. Such training enhancement likely would improve inter-rater reliability, and thus ensure that the tool could be applied more reliably in an accreditation or evaluation system in the real world.

Third, experience with the tool has also suggested elements of it that could benefit from clearer definitions. Precise, technical specifications are a critical element of any quality measurement system, but such definitions typically are finalized following field testing of an instrument. Better specifications could improve the reliability and validity of the tool in the future.

Fourth, experience with the tool has also demonstrated that "accuracy" and "comprehensiveness" may not be entirely distinct. In some cases, the inaccuracies were not entirely "wrong." For example, a site that discussed hypercholesterolemia as a complication of diabetes received a positive score on that criterion in comprehensiveness and therefore was scored (in the denominator) on that item in the accuracy section. If that site then failed to explain the different types of cholesterol and the appropriate low-density lipoprotein (LDL) target levels, it did not receive a positive score in accuracy, despite the fact that no "erroneous" information was presented. Some might argue that this is more a failure of comprehensiveness than accuracy, whereas the site that explains LDL but suggests the wrong target level is scored in the same way under this tool. Further research to refine the scoring system of this tool would be useful (see "Future Research Directions" section below).

Finally, evaluating international sites was a challenge because some of the recommendations may be different in other countries due to different standards of practice. For example, one of the most-basic issues in diabetes is defining what constitutes a diagnosis of the condition. The World Health Organization definition relies on a fasting blood glucose threshold of 140 mg/dL, whereas ADA—the accepted standard in the United States—uses a more-aggressive target of 126 mg/dL. Ultimately, we decided to include foreign-sponsored sites in the analysis under a US-developed system because this is an evaluation primarily for use by people in the United States and global access to different sites means that it is just as easy for an American to look at the DiabetesAustralia.com Web site as the ADA's Web site. However, because our review was being conducted concurrently with that of the external reviewer, that judgment was applied inconsistently between the 2 reviewers.

With alpha testing concluded, a beta test that addressed the issues above could vastly improve the inter-rater reliability, a key attribute of future successful implementation of any tool designed to offer an objective, systematic method. In addition, it may be worthwhile to consider eliminating, amending, or replacing items for which the kappa statistic was not statistically significant, which included 2 process criteria (updating process and timely update), 7 comprehensiveness criteria (exercise, acute episodes, foot care, dyslipidemia, care of children, prevention, and obesity) and 4 accuracy measures (Type 1 versus Type 2, secondary causes, cholesterol tests, and warning signs).

Examination of scores by evaluative section reveals some additional interesting findings. Comprehensiveness scores were substantially higher (58% and 59% median and mean, respectively) than accuracy scores (43% and 44%). This finding differs from the RAND/CHCF study [17] that evaluated "coverage" and "correctness," and found that Web sites were more likely to be accurate than to cover the clinical terrain comprehensively. As stated above, one of the areas for further clarification in this tool is the distinction between comprehensiveness and accuracy. The difference in terminology between the Diabetes Quality of Internet Information tool and the RAND tool also may be more than simply a semantic distinction. RAND's goal of assessing "correctness" perhaps speaks more directly to the distinction between erroneous and correct information. In contrast, "accuracy" is a broader goal that relates more to the degree of specificity of the information provided in helping consumers to understand a condition and change behaviors. Because our tools address different clinical conditions, a more thorough comparison of the individual criteria is difficult.

There was little correlation among the various criteria. One would anticipate that this type of index would have criteria independent of each other. Perhaps what was surprising was how few criteria had correlations of 0.50 or higher. Out of 820 possible correlations, only 12 had at least this modest correlation (contact author for a correlation matrix). None of the structural measures correlated at this level with any of the accuracy or comprehensiveness characteristics. Three of the structural measures were correlated with each other (content generation explanation, identification and disclosure, and peer review) in the 0.55 to 0.65 range. The only other correlations above 0.60 between any 2 of the comprehensiveness or accuracy criteria were the comprehensiveness criteria of retinopathy and nephropathy (at 0.76), and neuropathy and nephropathy (at 0.67); neuropathy and retinopathy were modest as well (0.58). Given these correlations, one might also expect that other complications in the comprehensiveness section would be somewhat high as well (eg, foot care and dyslipidemia), but none of the correlations among other criteria were higher than the 0.40 range.

## Limitations

Limitations that could have affected the results of this research fall primarily into 2 categories: sample and search strategy, and site review and evaluation.

### *Sample and Search Limitations*

The sampling had 3 limitations.

First, as described in the methods, the goal of the search strategy was to identify the most-popular sites for diabetes information, the rationale behind the selection of the Direct Hit search engine. However, there is no guarantee of Web site popularity because Direct Hit considers its search algorithm proprietary and therefore does not make it available for public critique.

Second, the popularity of some developers of Web site content may not be accessible through standard search engines, particularly with respect to information products licensed by content companies to consumer portals.

Third, the goal to freeze sites at a single point in time was not successful. It was time-consuming to freeze each individual page, a factor unrelated to the feasibility of the tool because the freezing was for research purposes rather than an intrinsic part of the evaluation system. This freezing process took many weeks to complete, thus eliminating its potential benefit. In retrospect, it would have been more efficient to go immediately to the evaluation phase of the research. The fact that some sites were frozen in November 2001 and others in January 2002 could affect the situational reliability of the evaluation, as some of the data could have changed. However, it is unlikely that this would have substantially changed the results. In the future, it may be valuable to do the opposite; that is, given the dynamic nature of the Web, it would be worthwhile to know how well sites update themselves to reflect new scientific information.

### *Review and Evaluation Limitations*

There were 6 limitations of the Web site review and evaluation.

First, because this research only addresses diabetes, one cannot generalize these findings to other aspects of health information.

Second, since no attempt was made to blind Web site names (it would have been too time-consuming for the purposes of this research), it is possible that reviewers' personal biases could have affected the evaluation scores.

Third, there was only one external reviewer. Therefore, the data included in this overall analysis also derive from the principal investigator's (JS's) evaluations. In order to minimize bias at the upper end of performance (since the top-scoring site—Healthwise—employs one of the authors), we only used the scores of the external reviewer for the top-performing sites.

Fourth, the study used the site's own description of its activities to determine the independent variables, which were not clear in all cases. One might think that the extensions of the Web sites (eg, .com, .org, .gov, and .edu) would provide much of that information, but there are many examples of instances where they are misleading. Many sites with .com extensions are not-for-profit. State and foreign government sites do not use .gov. Some state government-sponsored Web sites are "housed" in academic institutions that have .edu extensions. In addition, the myriad subsidiary arrangements sometimes make it difficult to discern for-profit and not-for-profit status, as some for-profit companies have nonprofit subsidiaries and vice versa.

Fifth, the criterion of "timely update" used an arbitrary time cut-off of 6 months. The rationale was to create some time cut-off to separate those sites that update their content regularly from those that do not. However, there is little reason to suspect that a site updated 26 weeks ago is better than a site updated 27 weeks ago.

Finally, the Internet is changing rapidly and is a moving target. Just as the state of the Internet has changed dramatically since this research began, many other changes can be expected in the near future that could change some of these findings.

### Future Research Directions

Future related research would be helpful in 2 areas: refinement of the existing diabetes tool and application of the diabetes tool to other conditions.

First, refinement of the existing tool primarily relates to addressing the issues raised in the reliability section above. More-precise technical specifications of the review criteria, more-thorough reviewer training, and a clearer distinction between accuracy and comprehensiveness would lead to an improved second version of the tool. A reexamination of the tool by the diabetes performance-measurement experts or an expert panel could allow the tool to provide even more differentiation among sites, particularly in the comprehensiveness section where there was less variation in scores. With that work completed, additional methodological research should be done on the index construction itself, as outlined above.

Second, with respect to the need for research on Web site evaluation tools for other conditions, one of the critical factors is dealing with varying degrees of an evidence base across diseases. Whereas treatment for diabetes has a relatively-strong evidence base—and some, like cardiovascular disease, probably are even stronger in that respect—other conditions have much more limited evidence (or it changes rapidly) on which a Web site can base its information. This has implications for criteria selection in terms of both what should be covered on a Web site (comprehensiveness) and precisely what the site should say (accuracy).

### Conclusions

There is wide variation in the accuracy and comprehensiveness of online diabetes information and no existing mechanism for consumers to get detailed, objective information about true Web site quality. Furthermore, this research also demonstrates the limited utility of using proxies such as sponsorship characteristics to help guide consumers in searching for health Internet information.

This research also highlights the alarming amount of inaccurate and incomplete Internet information on diabetes. Given the increase in consumer use of the Web to make health care decisions, the potential threats to patient care are substantial. If diabetes information is incomplete, a consumer may not be aware of all the various complications of diabetes and thus not know to get tested for certain conditions. If a consumer finds inaccurate information on the Web, he or she may not be aware, for example, of the symptoms that indicate the onset of an acute diabetic event.

Objective review of performance in producing health information quality, expressed in terms of accuracy and comprehensiveness of information, can offer consumers a tangible and useful tool in navigating the online health universe.

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## Conflicts of Interest

The principal investigator, JS, is currently employed by Healthwise (one of the evaluated Web sites), but the review of this site (as well as all other sites that received high scores) was conducted by the external reviewer without influence from the author. Exclusion of this site from the analysis only changed the mean score by half of one percentage point.

## Appendix 1

### Scoring by section; ordered first by overall score and second by outcome total.

**Table A1.** Scoring by section; ordered first by overall score and second by outcome total

| **Web Site** | | **Scoring Section** | | | | **Overall Score, %** |
|---|---|---|---|---|---|---|
| **Name** | **URL** | **Process Total, %** | **Outcome Total (Outcome Score), %** | **Comprehensiveness, %** | **Accuracy, %** | |
| Healthwise* | http://www.healthwise.org/p_demos | 86 | 97 | 96 | 100 | 95 |
| Diabetes Living | http://www.diabetesliving.org/ | 57 | 97 | 96 | 100 | 90 |
| Canadian Diabetes Association | http://www.diabetes.ca/ | 86 | 88 | 92 | 80 | 88 |
| American Diabetes Association | http://www.diabetes.org/ | 86 | 85 | 88 | 78 | 85 |
| MayoClinic.com | http://www.mayoclinic.com/ | 71 | 82 | 92 | 60 | 80 |
| Wisconsin Department of Health | http://www.dhfs.state.wi.us/health/diabetes | 71 | 79 | 88 | 56 | 78 |
| Helios Health | http://www.helioshealth.com/diabetes | 86 | 76 | 79 | 67 | 78 |
| DrKoop.com | http://www.drkoop.com/ | 100 | 70 | 79 | 44 | 75 |
| MEDLINEplus | http://www.nlm.nih.gov/medlineplus | 57 | 49 | 83 | 67 | 75 |
| South Dakota DHHS | http://www.sddiabetes.net/ | 57 | 78 | 79 | 75 | 74 |
| Diabetes Insight | http://www.diabetic.org.uk/ | 29 | 82 | 83 | 78 | 73 |
| Joslin Diabetes Center | http://www.joslin.harvard.edu/ | 29 | 82 | 83 | 78 | 73 |
| Health A to Z | http://www.healthatoz.com/atoz/Diabetes | 57 | 76 | 75 | 78 | 73 |
| Net Doctor | http://www.netdoctor.co.uk/ | 56 | 76 | 79 | 70 | 73 |
| Canadian Medical Association Journal | http://www.cma.ca/cmaj | 71 | 74 | 83 | 50 | 73 |
| Diabetes Australia | http://www.diabetesaustralia.com.au/ | 71 | 71 | 83 | 29 | 71 |
| University of Massachusetts Medical School<br>Diabetes Handbook | http://www.umassmed.edu/diabeteshandbook | 43 | 73 | 83 | 44 | 68 |
| University of Pennsylvania Health System | http://www.uphs.upenn.edu/health | 57 | 70 | 71 | 67 | 68 |
| South Carolina Diabetes Association | http://www.musc.edu/diabetes | 14 | 77 | 75 | 86 | 66 |
| Diabetes News | http://www.diabetesnews.com/ | 0 | 79 | 83 | 67 | 65 |
| Diabetes Mall | http://www.diabetesnet.com/ | 14 | 76 | 75 | 78 | 65 |
| NIDDK | http://www.niddk.nih.gov/ | 57 | 67 | 71 | 56 | 65 |
| Texas Department of Health | http://www.tdh.state.tx.us/diabetes | 57 | 67 | 75 | 44 | 65 |
| Focus on Diabetes | http://www.focusondiabetes.com/ | 71 | 64 | 63 | 67 | 65 |
| WebMD | http://my.webmd.com/index | 29 | 71 | 75 | 60 | 63 |
| Colorado Health Net | http://www.coloradohealthnet.org/diabetes | 29 | 70 | 75 | 56 | 63 |
| Diabetes Guidelines Europe | http://www.staff.ncl.ac.uk/philip.home | 43 | 67 | 67 | 67 | 63 |
| National Service Framework for Diabetes | http://www.doh.gov.uk/nsf/diabetes | 57 | 64 | 75 | 33 | 63 |

| Web Site | | Scoring Section | | | | Overall Score, % |
|---|---|---|---|---|---|---|
| Name | URL | Process Total, % | Outcome Total (Outcome Score), % | Comprehensiveness, % | Accuracy, % | |
| International Diabetes Institute | http://www.diabetes.com.au/ | 14 | 72 | 75 | 63 | 62 |
| Diabetic Retinopathy | http://medweb.bham.ac.uk/easdec | 43 | 66 | 71 | 50 | 62 |
| Diabetes Program of Ohio | http://www.diabetesohio.org/ | 29 | 68 | 88 | 20 | 61 |
| Online Med Info | http://www.onlinemedinfo.com/ | 14 | 70 | 67 | 78 | 60 |
| Virginia Mason | http://www.virginiamason.org/ | 29 | 66 | 74 | 38 | 59 |
| Diabetes Scene | http://www.banting.com/ | 43 | 63 | 63 | 63 | 59 |
| Doc Guide.com | http://www.docguide.com/ | 0 | 68 | 79 | 40 | 56 |
| Annenberg Center for Health Services | http://www.annenberg.org/achs | 29 | 63 | 67 | 50 | 56 |
| Diabetic Digest | http://www.thediabeticdigest.com/ | 29 | 62 | 75 | 30 | 56 |
| Merck Manual | http://www.merck.com/pubs/mmanual_home | 57 | 56 | 67 | 30 | 56 |
| Diabetic.com | http://www.diabetic.com/ | 0 | 68 | 67 | 61 | 55 |
| Healing Well | http://www.healingwell.com/ | 29 | 58 | 63 | 44 | 53 |
| Pancreatic Diseases | http://66.70.75.130/bin/ctwe | 86 | 45 | 46 | 43 | 53 |
| Oregon Department of Health | http://www.ohd.hr.state.or.us/diabetes | 71 | 47 | 42 | 67 | 51 |
| Diabetes Mellitus | http://www.diabetes-mellitus.org/ | 0 | 61 | 67 | 64 | 50 |
| BBC | http://www.bbc.co.uk/health/diabetes | 14 | 58 | 63 | 43 | 50 |
| Lilly Diabetes | http://www.lillydiabetes.com/ | 29 | 55 | 58 | 44 | 50 |
| Medical College of Wisconsin | http://healthlink.mcw.edu/article | 71 | 45 | 50 | 29 | 50 |
| Diabetes Institutes Foundation | http://www.dif.org/ | 14 | 57 | 63 | 33 | 49 |
| About.com | http://www.diabetes.about.com/ | 14 | 56 | 58 | 50 | 49 |
| Novo Nordisk | http://www.diabetesdiary.com/ | 43 | 50 | 54 | 38 | 49 |
| Yahoo | http://www.yahoo.com/health/diseases | 14 | 55 | 58 | 44 | 48 |
| International Diabetes Foundation | http://www.idf.org/ | 0 | 28 | 67 | 29 | 47 |
| East Texas Medical Center | http://www.etmc.org/diabetes | 14 | 53 | 58 | 38 | 46 |
| Defeat Diabetes | http://www.defeatdiabetes.org/ | 29 | 48 | 58 | 22 | 45 |
| Mamas Health | http://www.mamashealth.com/diabetes3 | 0 | 53 | 58 | 38 | 44 |
| Black Women's Health | http://www.blackwomenshealth/diabetes | 29 | 47 | 58 | 13 | 44 |
| Reverse Diabetes | http://www.reversingdiabetes.org/ | 0 | 53 | 58 | 33 | 43 |
| Medical Data | http://www.medicaldata.com/ | 14 | 50 | 54 | 33 | 43 |
| Eastern Virginia Medical School | http://www.evms.edu/diabetes | 29 | 46 | 50 | 25 | 43 |
| Diabetes News on the Net | http://www.diabetesnewsonthenet.com/ | 0 | 52 | 54 | 43 | 42 |

| Web Site | | Scoring Section | | | | Overall Score, % |
|---|---|---|---|---|---|---|
| Name | URL | Process Total, % | Outcome Total (Outcome Score), % | Comprehensiveness, % | Accuracy, % | |
| University of Michigan | http://www.med.umich.edu/1libr/topics/diabetes | 0 | 52 | 58 | 29 | 42 |
| New Zealand Guidelines Group | http://www.nzgg.org.nz/library | 43 | 41 | 46 | 20 | 42 |
| Diabetes Education Network | http://www.healthtalk.com/den/index | 0 | 50 | 46 | 67 | 41 |
| Diabetes at Mercy Medical Center | http://www.diabetes.mdmercy.com/ | 0 | 50 | 54 | 33 | 41 |
| International Diabetes Center | http://www.idcpublishing.com/ | 0 | 50 | 54 | 38 | 41 |
| Dr. Mirkin | http://www.drmirkin.com/diabetes | 57 | 38 | 46 | 13 | 41 |
| 4Women.gov | http://www.4woman.gov/faq/diabetes | 14 | 45 | 50 | 33 | 40 |
| Endocrinologist.com | http://www.endocrinologist.com/diabetes | 0 | 48 | 54 | 29 | 39 |
| Diab Care | http://www.diabcare.de/diabetes | 0 | 47 | 54 | 25 | 38 |
| Utah Diabetes Control Program | http://www.health.state.ut.us/cfhs | 0 | 43 | 50 | 17 | 35 |
| CDC | http://www.cdc.gov/diabetes/index | 43 | 33 | 33 | 33 | 35 |
| Diabetes Therapies.com | http://www.diabetes-therapies.com/ | 0 | 41 | 42 | 38 | 33 |
| Solaris | http://www.solarishs.org/diabetes | 0 | 41 | 42 | 38 | 33 |
| Endocrine Web | http://www.endocrineweb.com/diabetes | 14 | 38 | 33 | 60 | 33 |
| IDD Trust International | http://www.iddtinternational.org/ | 14 | 38 | 33 | 60 | 33 |
| Paralumun | http://www.paralumun.com/diabetes | 0 | 39 | 38 | 43 | 32 |
| University of Minnesota Diabetes Institute | http://www.diabetesinstitute.org/ | 0 | 39 | 42 | 25 | 31 |
| BD Diabetes | http://www.bddiabetes.com/ | 14 | 36 | 42 | 0 | 31 |
| American Podiatric Medical Association | http://www.apma.org/topics/Diabetes | 0 | 37 | 38 | 33 | 29 |
| Tin Man | http://www.tinman.com/diabetes | 0 | 37 | 38 | 33 | 29 |
| Diabetes and CAD | http://www.chebucto.ns.ca/Health/CPRC/diabetes | 14 | 32 | 29 | 50 | 29 |
| Your Health Your Hands | http://www.yourhealthyourhands.com/diabetes | 29 | 30 | 33 | 0 | 29 |
| Diabetes Control Center | http://www.dr-diabetes.com/ | 29 | 28 | 25 | 40 | 28 |
| Diabetes Foundation of Mississippi | http://www.msdiabetes.org/ | 0 | 33 | 38 | 17 | 27 |
| Healthy Wave-Diabetes | http://www.healthywave.com/healthbeat/diabetes | 29 | 22 | 25 | 0 | 24 |
| University of Manitoba | http://www.umanitoba.ca/outreach/drtc | 43 | 19 | 21 | 0 | 24 |
| FIT Foundation | http://www.diabetestrends.com/ | 29 | 21 | 25 | 0 | 23 |

| Web Site | | Scoring Section | | | | Overall Score, % |
|---|---|---|---|---|---|---|
| Name | URL | Process Total, % | Outcome Total (Outcome Score), % | Comprehensiveness, % | Accuracy, % | |
| Medical Library of Utah | http://www.medlib.med.utah.edu/ | 43 | 14 | 17 | 0 | 20 |
| South Carolina Diabetes Prog | http://www.musc.edu/diabetes | 14 | 19 | 13 | 67 | 18 |
| Family's Guide to Diabetes | http://diabetes.cbyc.com/ | 0 | 21 | 17 | 50 | 17 |
| Geocities.com | http://www.geocities.com/ | 0 | 19 | 21 | 0 | 15 |

[*] Disclosure: the principal investigator (JS) is currently employed by Healthwise, but the review of this site (as well as all other sites that received high scores) was conducted by the external reviewer without influence from the author. Exclusion of this site from the analysis only changed the mean score by half of one percentage point.

## Appendix 2

## Kappa statistics for each criterion.

**Table A2.** Kappa statistics for each criterion

| Criterion | Agreement | Expected Agreement | Kappa | *P* | |
|---|---|---|---|---|---|
| **Process measures average** | **72.38%** | **56.57%** | **0.3422** | **Significant** | |
| | Content generation explanation | 66.67% | 52.00% | 0.3056 | [illegible] |
| | Identification & disclosure | 86.67% | 50.00% | 0.7333 | < [illegible] |
| | Referenced material | 66.67% | 51.56% | 0.3119 | [illegible] |
| | Peer review | 66.67% | 51.78% | 0.3088 | [illegible] |
| | Updating process | 80.00% | 76.67% | 0.1429 | [illegible] |
| | Content dating | 66.67% | 50.00% | 0.3333 | [illegible] |
| | Timely update | 73.33% | 64.00% | 0.2593 | [illegible] |
| | **Comprehensiveness average** | **79.45%** | **65.91%** | **0.4168** | [illegible] |
| | Screening | 80.00% | 55.56% | 0.5500 | [illegible] |
| | Glycemia tests | 80.00% | 58.89% | 0.5135 | < [illegible] |
| | Exercise | 90.00% | 90.44% | -0.0465 | [illegible] |
| | Acute episodes | 73.33% | 64.22% | 0.2547 | [illegible] |
| | Secondary diabetes | 76.67% | 49.11% | 0.5415 | < [illegible] |
| | Foot care | 73.33% | 68.67% | 0.1489 | [illegible] |
| | Dyslipidemia | 60.00% | 52.89% | 0.1509 | [illegible] |
| | Smoking cessation | 70.00% | 49.11% | 0.4105 | [illegible] |
| | Nephropathy | 96.67% | 90.44% | 0.6512 | < [illegible] |
| | Retinopathy | 96.67% | 90.44% | 0.6512 | < [illegible] |
| | Immunization | 93.33% | 81.78% | 0.6341 | < [illegible] |
| | Insulin administration | 60.00% | 42.22% | 0.3077 | [illegible] |
| | Oral medications | 80.00% | 60.67% | 0.4915 | [illegible] |
| | Glucose monitoring | 80.00% | 63.33% | 0.4545 | [illegible] |
| | Care of children | 73.33% | 64.22% | 0.2547 | [illegible] |
| | Gestational diabetes | 86.67% | 76.89% | 0.4231 | [illegible] |
| DCCT (Diabetes Control & Complications Trial) implications | 76.67% | 51.33% | 0.5205 | .0021 | |
| | UKPDS (United Kingdom Prevention of Diabetes Study) implications | 86.67% | 72.00% | 0.5238 | [illegible] |
| | Nutrition | 96.67% | 84.67% | 0.7826 | < [illegible] |

| Criterion | Agreement | Expected Agreement | Kappa | *P* | |
|---|---|---|---|---|---|
| | Insulin/glucose explanation | 76.67% | 63.33% | 0.3636 | 90. |
| | Prevention | 53.33% | 44.67% | 0.1566 | 24. |
| | Psychological aspects | 80.00% | 57.78% | 0.5263 | 80. |
| | Neuropathy | 90.00% | 79.33% | 0.5161 | 10. |
| | Obesity | 76.67% | 70.00% | 0.2222 | 31. |
| **Accuracy average** | **81.33%** | **66.62%** | **0.3979** | **Significant** | |
| | Type 1 vs Type 2 | 80.00% | 76.00% | 0.1667 | 15. |
| | Secondary causes | 96.67% | 96.67% | 0.0000 | 05. |
| | Diagnostic tests | 80.00% | 50.00% | 0.6000 | < 10. |
| | HbA1c test | 76.67% | 55.33% | 0.4776 | 40. |
| | Albumin tests | 90.00% | 79.33% | 0.5161 | 10. |
| | Cholesterol tests | 76.67% | 70.00% | 0.2222 | 31. |
| | Warning signs | 60.00% | 46.44% | 0.2531 | 95. |
| | Hypoglycemia prevention | 73.33% | 56.00% | 0.3939 | 70. |
| | Oral medications | 90.00% | 62.44% | 0.7337 | < 10. |
| | Rezulin | 90.00% | 74.00% | 0.6154 | < 10. |
| **Outcome composite average** | **80.00%** | **66.12%** | **0.4112** | **Significant** | |
| **Overall average** | **78.70%** | **64.49%** | **0.3994** | **Significant** | |

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## Abbreviations

**ADA:** American Diabetes Association

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Original Paper

# What Are Patients Seeking When They Turn to the Internet? Qualitative Content Analysis of Questions Asked by Visitors to an Orthopaedics Web Site

Kristen S Shuyler[1], MA; Kristin M Knight[2], BS

[1]University of Washington, Program for Educational Transformation Through Technology, Seattle WA, USA
[2]University of Washington, School of Medicine, Seattle WA, USA

**Corresponding Author:**
Kristen S Shuyler, MA
Program for Educational Transformation Through Technology
University of Washington
Seattle WA Box 353080
USA
Email: kshuyler@u.washington.edu

## Abstract

**Background:** More people than ever are turning to the Internet for health-related information, and recent studies indicate that the information patients find online directly affects the decisions they make about their health care. Little is known about the information needs or actual search behavior of people who use the Internet for health information.

**Objective:** This study analyzes what people search for when they use a health-education Web site offering information about arthritis, orthopaedics, and sports-medicine topics. Additionally, it determines who is performing these searches: is it patients, friends or relatives of patients, or neither? Finally, it examines the similarities and differences among questions submitted by Web site visitors from different countries.

**Methods:** Content analysis was performed on 793 free-text search queries submitted to a patient-education Web site owned and operated by the Department of Orthopaedics and Sports Medicine at the University of Washington Medical Center. The 793-query data set was coded into 3 schemes: (1) the purpose of the query, (2) the topic of the query, and (3) the relationship between the asker of the query and the patient. We determined the country from which each query was submitted by analyzing the Internet Protocol addresses associated with the queries.

**Results:** The 5 most frequent reasons visitors searched the Web site were to seek: (1) information about a condition, (2) information about treatment, (3) information about symptoms, (4) advice about symptoms, and (5) advice about treatment. We were able to determine the relationship between the person submitting the query and the patient in question for 178 queries. Of these, the asker was the patient in 140 cases, and the asker was a friend or relative of the patient in 38 cases. The queries were submitted from 34 nations, with most coming from the United States, Australia, the United Kingdom, and Canada. When comparing questions submitted from the United States versus those from all other countries, the 3 most frequent types of questions were the same for both groups (and were the top 3 question types listed above).

**Conclusions:** These results provide the University of Washington Department of Orthopaedics and Sports Medicine, as well as other organizations that provide health-information Web sites, with data about what people around the world are seeking when they turn to the Internet for health information. If Web site managers can adapt their health-information Web sites in response to these findings, patients may be able to find and use Internet-based health information more successfully, enabling them to participate more actively in their health care.

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**KEYWORDS**

Internet; information storage and retrieval; patients; orthopedics

## Introduction

Millions of people are turning to the Internet for health-related information, and the information they find often directly affects the decisions they make about their health care. A recent study estimated that 73 million Americans, or 62% of Americans with access to the Internet at the time, have used the Internet to search for medical information or other information relevant to their health care [1]. Another study estimated that 12.34 million health-related Web searches are conducted worldwide every day [2]. People often turn to the Internet for health and medical information because of its convenience and for the opportunities it provides for communication [3]. Many people use the Internet to supplement the information given to them by their physician [1,4], to become more involved in their health care decisions [5], or to become more educated about their condition or the condition of a friend or relative.

The medical information that people find on the Internet may affect their health care decisions, health status, and mental status. Two recent studies reported on Americans who have searched the Internet for medical information, termed "health seekers." Ninety-two percent of health seekers reported that the health information they obtained during their last Internet search was useful and relevant [4], and 68% reported that the medical information they found on the Internet played an influential role in the health care decisions they made for themselves or their loved ones [1]. In 2002, 62% of health seekers said the information they found online improved how they cared for themselves, up from 48% in 2000 [1]. People may be able to meet some of their psychological needs related to their health care by using Internet-based tools to answer their questions [3]. Interacting with others online may also lead to improved health status and decreased health care utilization, according to a recent study that examined e-mail discussion groups [5].

Research suggests that the Internet has revolutionized the way patients access health care information, learn more about their conditions, and make health care decisions. Little data exists, however, about the ways that patients actually use the Web [6,7], or about patients' information needs when they use the Internet, such as the "reasons behind online information-seeking" and the "behavior of health users" on the Internet [6]. To explore patients' information needs when they consult the Internet, this study analyzes what people search for when they use a patient-education Web site operated by the Department of Orthopaedics and Sports Medicine at the University of Washington Medical Center. Additionally, it determines who is performing these searches, and it compares questions submitted by Web site visitors from around the world.

Recent studies asking similar questions have analyzed the topics of e-mails sent to doctors [8,9] and the data from surveys asking about patients' Web searches for medical information [10]. Our study builds on this previous work by investigating the actual searches performed by one specific set of Internet users—those who visit the University of Washington Department of Orthopaedics and Sports Medicine Web site. The University of Washington Department of Orthopaedics and Sports Medicine, as well as other organizations providing health information Web sites, can use these data about these users to develop their understandings of the information needs of patients in general, and to improve their Web sites to provide effective educational materials for their users. In turn, patients who are knowledgeable about their health can participate more actively with their physicians in determining a health care plan that is best suited for them.

## Methods

Content analysis was performed on free-text queries submitted to the Web site of the University of Washington Department of Orthopaedics and Sports Medicine [11], which features multimedia information on arthritis, orthopaedics, and sports-medicine topics. The Web site, which has been operating since 1995, provides articles and videos on over 200 topics to an average of 4000 visitors a day worldwide. The goal of the Web site is "to offer patient-education materials that support users' self-directed learning and help them answer their questions" [12]. In addition to browsing the Web site, visitors can query it in 3 ways: (1) by conducting a simple keyword search, (2) by e-mailing the Web site manager, or (3) by searching the Web site with the *Ask a Question* function (see Figure 1 and Figure 2 for screenshots of the search box page and the search results page). This search function was built specifically for this Web site, after informal analysis of searches performed in the keyword box revealed a high number of long queries resembling questions. This study analyzes the queries users submitted to the Ask a Question function, because that function encourages the users to describe what they are looking for in more detail than the small keyword search box does.

When using the Ask a Question function, users type free-text questions into a search box that is large compared to typical keyword search boxes. A simple computer program built for the Ask a Question function parses these free-text questions to make them compatible with the program's search algorithm. The users receive search results consisting of similar questions to which the Web site already offers answers. They can then choose which question/answer is the most relevant or similar to their information need. Implemented in November 2001, the Ask a Question system handles more than 1000 questions each month.

### Sample

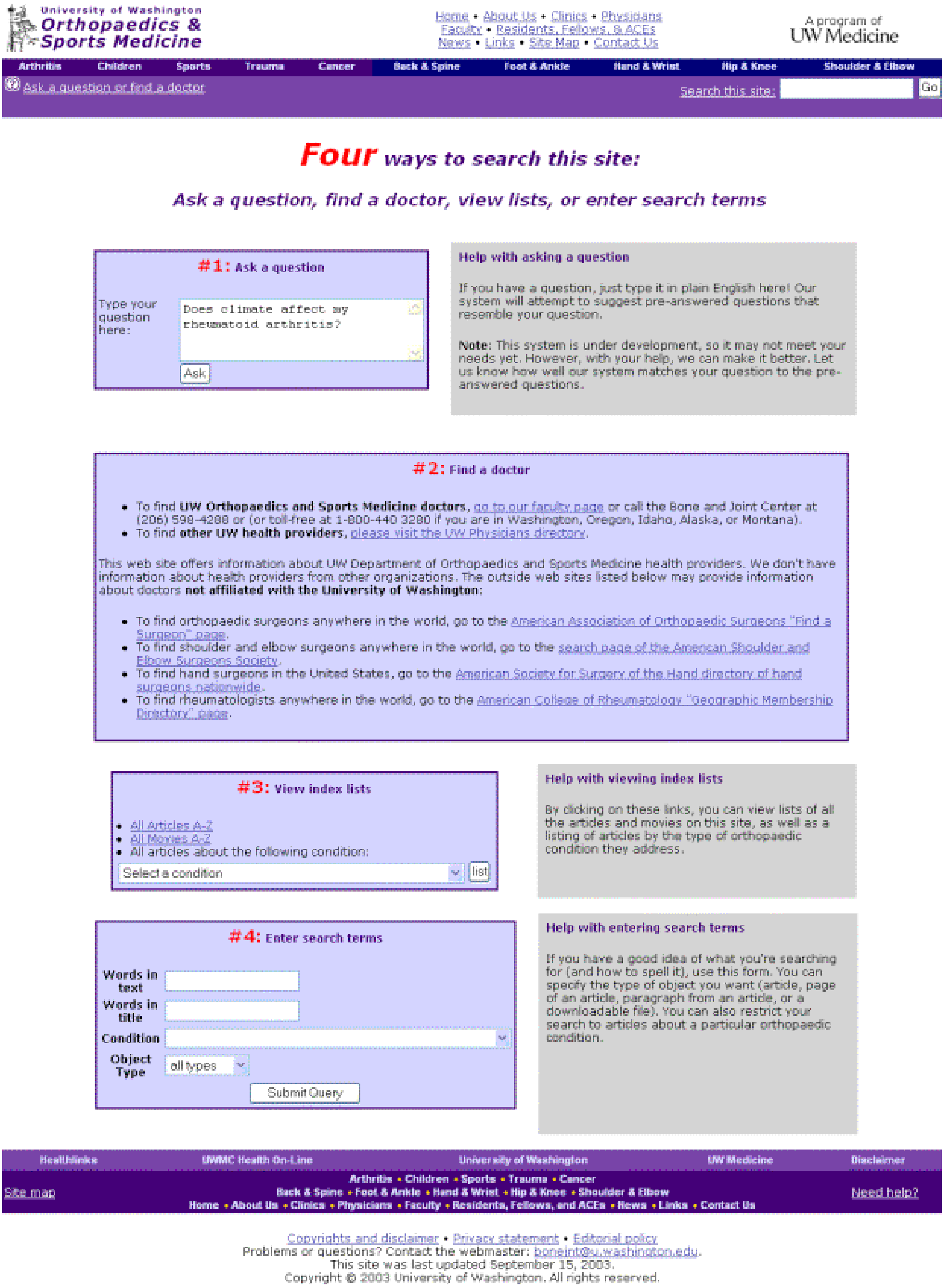
The questions examined in this study were obtained by a systematic sample of all the free-text queries submitted to the Web site's Ask a Question function during March and June of 2002.

March and June were selected so the data set would consist of recent queries. May was omitted because the queries from that month were used to develop the coding scheme. April was omitted because it had an unusually-high number of submissions due to a campus event related to the Web site.

All search queries submitted during March and June were retrieved from the Web site's log files. We also obtained the date and time each query was submitted and the Internet Protocol (IP) address (the unique numeric address of the computer from which each query was submitted [13]).From the

IP address, we were able to determine the country of origin of each submission.

**Figure 1.** Web site search-box page



**Four** ways to search this site:

Ask a question, find a doctor, view lists, or enter search terms

**#1:** Ask a question

Type your question here: Does climate affect my rheumatoid arthritis?

**Help with asking a question**

If you have a question, just type it in plain English here! Our system will attempt to suggest pre-answered questions that resemble your question.

**Note:** This system is under development, so it may not meet your needs yet. However, with your help, we can make it better. Let us know how well our system matches your question to the pre-answered questions.

**#2:** Find a doctor

- To find **UW Orthopaedics and Sports Medicine doctors**, go to our faculty page or call the Bone and Joint Center at (206) 598-4288 or (or toll-free at 1-800-440 3280 if you are in Washington, Oregon, Idaho, Alaska, or Montana).
- To find **other UW health providers**, please visit the UW Physicians directory.

This web site offers information about UW Department of Orthopaedics and Sports Medicine health providers. We don't have information about health providers from other organizations. The outside web sites listed below may provide information about doctors **not affiliated with the University of Washington**:

- To find orthopaedic surgeons anywhere in the world, go to the American Association of Orthopaedic Surgeons "Find a Surgeon" page.
- To find shoulder and elbow surgeons anywhere in the world, go to the search page of the American Shoulder and Elbow Surgeons Society.
- To find hand surgeons in the United States, go to the American Society for Surgery of the Hand directory of hand surgeons nationwide.
- To find rheumatologists anywhere in the world, go to the American College of Rheumatology "Geographic Membership Directory" page.

**#3:** View index lists

- All Articles A-Z
- All Movies A-Z
- All articles about the following condition:

**Help with viewing index lists**

By clicking on these links, you can view lists of all the articles and movies on this site, as well as a listing of articles by the type of orthopaedic condition they address.

**#4:** Enter search terms

**Help with entering search terms**

If you have a good idea of what you're searching for (and how to spell it), use this form. You can specify the type of object you want (article, page of an article, paragraph from an article, or a downloadable file). You can also restrict your search to articles about a particular orthopaedic condition.

Problems or questions? Contact the webmaster: boneint@u.washington.edu.

This site was last updated September 15, 2003.

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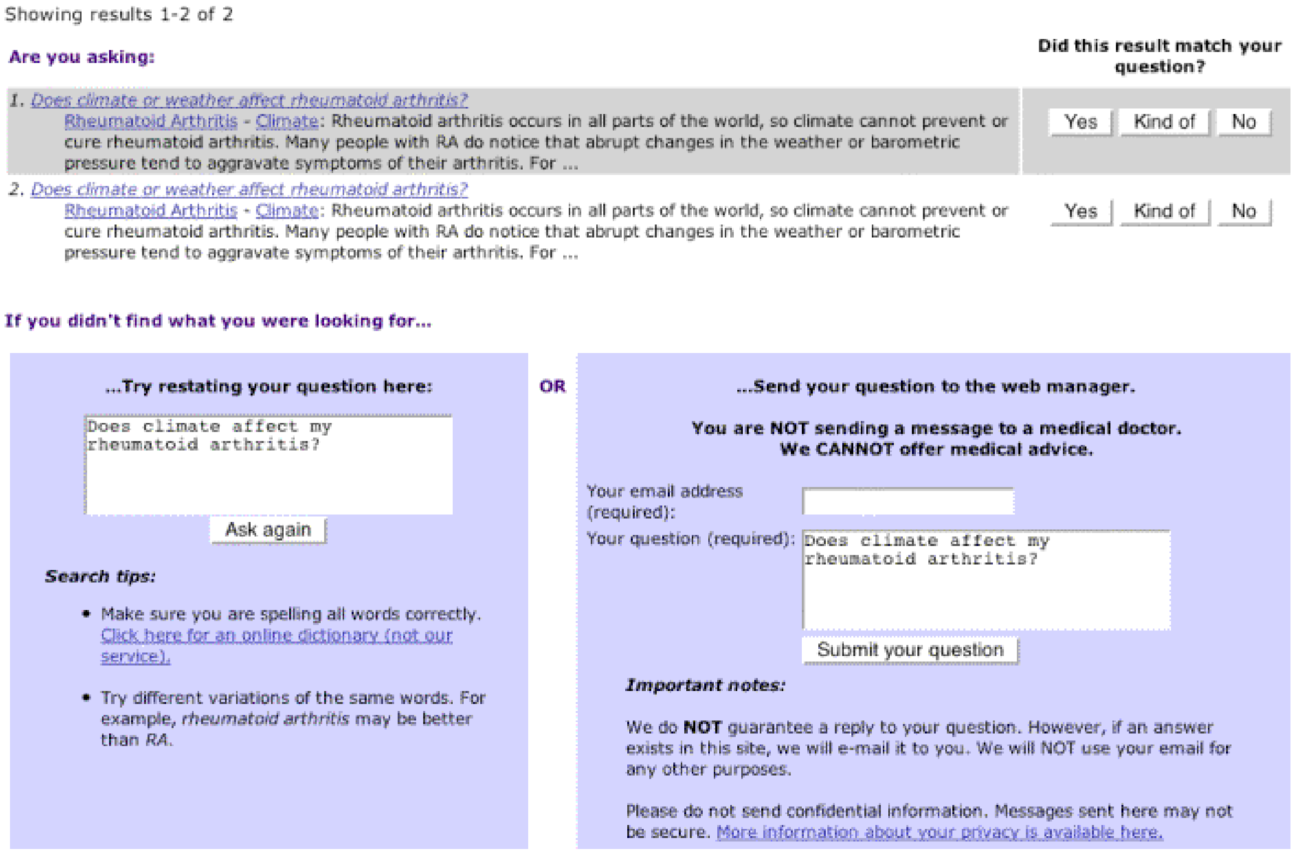
In March and June, respectively, 2290 and 2208 queries were submitted to the site. These queries were imported into Excel, sorted by IP address and time, and examined. Identical questions submitted from the same IP address were deleted, as were extremely-similar (but not identical) questions submitted from the same IP address within a period of 24 hours. Queries submitted with no text and those submitted from askers who were not patients nor were asking for patients were deleted. Examples of queries from people who were not patients nor asking for patients include queries from students, queries of a derogatory or crude nature, or queries that did not pertain to the Web site or its contents in any way. Queries submitted by staff members when testing the site were deleted. After these deletions were made, the resulting data set consisted of 885 and 702 queries for March and June, respectively, for a total of 1587 queries.

To obtain the sample on which our analyses were conducted, the queries were sorted by the date and time of submission (oldest to most recent) and every other query was selected (in March we started with the first query and in June we started with the second). This systematic sampling method was used so that queries would be selected from the full range of the month, from start to finish, to account for any possible changes in visitors' behavior over this period (eg, if people respond to the beginning of a month with a renewed interest in their health and therefore ask different types of questions). The resulting sample consisted of 793 queries.

**Figure 2.** Web site search-results page



Showing results 1-2 of 2

**Are you asking:**

**Did this result match your question?**

1. *Does climate or weather affect rheumatoid arthritis?*
   Rheumatoid Arthritis - Climate: Rheumatoid arthritis occurs in all parts of the world, so climate cannot prevent or cure rheumatoid arthritis. Many people with RA do notice that abrupt changes in the weather or barometric pressure tend to aggravate symptoms of their arthritis. For ...
2. *Does climate or weather affect rheumatoid arthritis?*
   Rheumatoid Arthritis - Climate: Rheumatoid arthritis occurs in all parts of the world, so climate cannot prevent or cure rheumatoid arthritis. Many people with RA do notice that abrupt changes in the weather or barometric pressure tend to aggravate symptoms of their arthritis. For ...

**If you didn't find what you were looking for...**

**...Try restating your question here:**

Does climate affect my rheumatoid arthritis?

***Search tips:***

- Make sure you are spelling all words correctly. Click here for an online dictionary (not our service).
- Try different variations of the same words. For example, *rheumatoid arthritis* may be better than *RA*.

**OR**

**...Send your question to the web manager.**

**You are NOT sending a message to a medical doctor.**
**We CANNOT offer medical advice.**

Your email address (required):

Your question (required): Does climate affect my rheumatoid arthritis?

***Important notes:***

We do **NOT** guarantee a reply to your question. However, if an answer exists in this site, we will e-mail it to you. We will NOT use your email for any other purposes.

Please do not send confidential information. Messages sent here may not be secure. More information about your privacy is available here.

## Content Analysis and Coding System

Because the underlying meanings of the questions submitted to the Web site were of interest (what users actually wanted to find, as opposed to the use of certain words or the number of words per query), a qualitative, descriptive approach was selected. We analyzed the queries by reading them and looking for themes and patterns, then developing a coding system to describe the data. These procedures are typical steps in content analysis. We decided content analysis was useful for this project because it is an unobtrusive analysis method, it can handle material that is not structured (and thus can tolerate free-text queries), and it can easily accommodate large amounts of data [14]. Content analysis has been utilized to investigate patients' needs and concerns in medical studies [15,16,17], but we have not found its use in studies of online health-information needs.

### *Development of Coding System*

To develop the coding system, a test set of queries submitted to the Ask a Question function during the month of May 2002 was retrieved from the Web site's log files and imported into Excel. After conducting the same process of deletions as described above, the resulting 951 queries were used to develop the coding scheme. The submissions were examined and a preliminary code was developed to reflect the overall trends observed in the data. As additional questions were examined and applied to the code, the coding system was altered and refined. During this process, the code was shared with a physician and a registered nurse, both of whom had extensive research experience, to obtain their feedback. The result was a coding system that was clear, concise, and descriptive of all the available data in the test set.

The coding system we developed consisted of 3 measures: (1) the asker's purpose in submitting the query, (2) the main topic addressed in the query, and (3) the relationship between the asker and patient. For the first measure, the asker's purpose in submitting the query, the 5 coding options included: (1) the asker was seeking advice or an opinion, (2) the asker was seeking an interpretation of information they already possessed, (3) the asker was seeking information (includes keyword searches performed using the Ask a Question function), (4) the asker was solely sharing information, and (5) the asker's purpose in submitting the question was unclear, or it didn't fit into any of the other categories. See Table 1 for examples of the 5 coding options.

The second measure, the main topic addressed in the question, consisted of 5 coding options: (1) questions with a main topic pertaining to physicians, support groups, or other resources, (2) questions asking about conditions (including syndromes), symptoms, and/or injuries, (3) questions that addressed treatments (including procedures), tests/labs, the process of diagnosis, prognosis, prevention, diet, exercise, medication, and/or lifestyle, (4) questions regarding anatomical structures, and (5) questions in which the main topic was unclear or did not fit into any of the above categories (see Table 1 for examples of the 5 coding options).

The third measure addressed the relationship between the asker and the patient in the question. The 3 codes were: (1) the asker self-identified as the patient, (2) the asker self-identified as a relative or friend of the patient, and (3) the relationship between the asker and patient could not be determined with the information provided (see Table 1 for examples of the 3 coding options).

**Table 1.** Coding options for 3 content analysis measures

| **Coding Options for Purpose of Query** | **Example From Data Set** |
|---|---|
| (1) Asker seeking advice or opinion | What should I eat if I have back pain? |
| (2) Asker seeking an interpretation | What does it mean when a neurosurgeon says 'You have a broken back'? |
| (3) Asker seeking information | How do you get arthritis? |
| (4) Asker is sharing information | I have rheumatoid arthritis. |
| (5) Purpose is unclear | Human growth hormone volunteer. |
| **Coding Options for Main Topic of Query** | **Example From Data Set** |
| (1) Physicians, support groups, and/or resources | Who is a good surgeon in Memphis for rotator cuff surgery? |
| (2) Conditions, symptoms, and/or injuries | What is compartmental syndrome? |
| (3) Treatments/procedures, tests/labs, process of diagnosis, prognosis, prevention, diet, exercise, medication, and/or lifestyle | How is arthritis diagnosed? |
| (4) Anatomical structures | What is a rotator cuff? |
| (5) Unclear or does not belong in 1-4 | Why are shorter people quicker than taller people besides artheritis [*sic*]? |
| **Coding Options for Relationship of Asker to Patient in Question** | **Example From Data Set** |
| (1) Asker is patient | What is my life expectancy with RA? |
| (2) Asker is a relative/friend of patient | How does my daughter avoid multiple shoulder dislocations? |
| (3) Relationship unknown | How does one know if the rotator cuff is injured or torn? |

### *Inter-rater Reliability of Coding System*

The reliability of this coding system was determined before it was applied to the actual 793-query data set. A sample of the actual data set (queries submitted during the months of March and June) was created using a systematic sampling technique. With the data sorted by date and time (oldest to most recent), every twentieth query was selected, starting with the second, creating a 40-query subset of the data set. Four coders applied the coding system to the 40-query sample. Besides the 2 authors, the coders included 2 individuals who were familiar with the Web site but not involved with this project. We introduced both people to the coding scheme and gave them the same instructions. Each coder then coded the pilot sample on the same day in a similar setting. The results were collected, entered into an Excel spreadsheet, and imported into SPSS (Statistical Package for Social Sciences). Fleiss' kappa statistical method was used to determine the inter-rater agreement for each of the 3 measures described above. Fleiss' kappa statistic is a measurement of inter-rater agreement among more than 2 raters when the coding is on a categorical scale [15]. For the first 2 measures (purpose and main topic of query), moderate agreement was achieved ($\kappa = 0.679$ and $\kappa = 0.697$, respectively) [18]. For the third measure (relationship between asker and patient), strong agreement was achieved ($\kappa = 0.763$) [18].

### *Application of Coding System*

Once the inter-rater reliability of the coding system was determined, the second author applied it to the 793-query data set, one measure at a time. Because the first measure, purpose of the query, was of the most interest to us, the same author coded it twice to determine intra-rater reliability, using Cohen's kappa statistic. Of the 793 entries coded twice by the same author, 29 discrepancies were found, resulting in a high level of agreement (κ = 0.915). The discrepancies were most often between the purposes "seeking advice" and "seeking information." The authors discussed the discrepancies and came to a unanimous decision on each one; in the process, the codes "seeking advice" and "seeking information" were further clarified. An inquiry was deemed to have the purpose of seeking information when the response elicited would not be need to be based on individual circumstances (ie, the response would be the same for multiple askers), whereas an inquiry that required a personalized response based on a patient's unique situation was categorized as asking advice.

After the "purpose" code had been applied to the data, the second author coded the data for the second measure, the main topic addressed in the query. All of the questions were then grouped by the code they received, examined in detail, and further categorized. For instance, all of the submissions that received a code of "1" pertained to physicians, support groups, and/or resources. After receiving the code of "1," they were further categorized by the specific topic they addressed (eg, physicians *or* support groups *or* resources).

Next, the data were coded for the third measure, the relationship between the asker and the patient in the question. The first code was assigned only when the asker explicitly identified himself/herself as the patient (eg, How should I treat my arthritis?). The second code was assigned only when the asker made it clear that they were asking for someone else (eg, My daughter was diagnosed with arthritis. How can I learn more about it?). The remaining queries were assigned the third code.

## Results

### Purpose of Queries

The most frequent purpose of the 793 queries was to seek information (73%). This was followed by seeking advice (23%), sharing information (3%), and seeking an interpretation (1%). For 5 of the questions (1%), the purpose was unclear (see Table 2).

**Table 2.** Purposes of queries

| **Purpose** | **Frequency (%)** * † |
|---|---|
| Seeking information | 576 (73%) |
| Seeking advice | 182 (23%) |
| Sharing information | 22 (3%) |
| Seeking an interpretation | 11 (1%) |
| Unclear | 5 (1%) |
| Total | 793 |

[*] The total values exceed 100% as 3 queries had 2 or more purposes.

[†] Percentages do not add up correctly due to rounding.

### Topic of Queries

Topics were determined for those queries with the 3 most frequent purposes (seeking information, seeking advice, or sharing information; a total of 780 queries). See Table 3 for the topics about which visitors to the site inquired and their frequencies.

**Table 3.** Topics of queries

| Topic | Frequency (%) [*] [†] |
|---|---|
| Condition | 247 (32%) |
| Treatment | 164 (21%) |
| Symptoms | 131 (17%) |
| Medication | 42 (5%) |
| Injury | 40 (5%) |
| Physician | 33 (4%) |
| Anatomy | 24 (3%) |
| Exercise | 22 (3%) |
| Tests/Labs | 20 (3%) |
| Diet | 10 (1%) |
| Prognosis | 10 (1%) |
| Diagnosis | 6 (1%) |
| Lifestyle | 5 (1%) |
| Resources | 5 (1%) |
| Prevention | 4 (1%) |
| Support groups | 1 (0%) |
| Unclear | 40 (5%) |
| Total | 780 |

[*] The total values exceed 100% as 20 queries had 2 or more topics.

[†] Percentages do not add up correctly due to rounding.

Of the 576 submissions with the purpose of seeking information, the most frequent topic was a condition (39%). Treatment was also a frequent topic (20%), followed by symptoms (11%) (see Table 4).

Of the 793-query dataset, 182 were seeking advice. The most frequent topic about which users sought advice was symptoms (28%). Other frequent topics for which advice was sought were treatment (26%), medication (12%), a condition (10%), and injury (6%) (see Table 4).

**Table 4.** Specific topics: seeking information, seeking advice, sharing information

| Topic | Frequency (%) of Queries Seeking Information * † | Frequency (%) of Queries Seeking Advice † ‡ | Frequency (%) of Queries Sharing Information † |
|---|---|---|---|
| Condition | 227 (39%) | 18 (10%) | 2 (9%) |
| Treatment | 114 (20%) | 48 (26%) | 3 (14%) |
| Symptoms | 64 (11%) | 51 (28%) | 16 (73%) |
| Injury | 30 (5%) | 10 (6%) | 1 (5%) |
| Physician | 25 (4%) | 9 (5%) | 0 |
| Anatomy | 24 (4%) | 1 (1%) | 0 |
| Medication | 22 (4%) | 21 (12%) | 0 |
| Tests/Labs | 14 (2%) | 6 (3%) | 0 |
| Exercise | 13 (2%) | 9 (5%) | 0 |
| Diagnosis | 6 (1%) | 0 | 0 |
| Diet | 6 (1%) | 4 (2%) | 0 |
| Resources | 5 (1%) | 0 | 0 |
| Prognosis | 4 (1%) | 6 (3%) | 0 |
| Prevention | 3 (1%) | 1 (1%) | 0 |
| Lifestyle | 1 (0%) | 4 (2%) | 0 |
| Support groups | 1 (0%) | 0 | 0 |
| Unclear | 33 (6%) | 3 (2%) | 0 |
| Total | 576 | 182 | 22 |

[*] The total values exceed 100% as 14 queries had 2 or more topics.

[†] Percentages do not add up correctly due to rounding.

[‡] The total values exceed 100% as 8 queries had 2 or more topics.

Twenty-two of the 793 questions had a sole purpose of sharing information. Of these, 16 (73%) were sharing about symptoms and 3 (14%) were sharing about treatment (see Table 4).

**Table 5.** Most frequent topics by most frequent purposes

| Seeking Information | Seeking Advice | Sharing Information |
|---|---|---|
| (1) Condition | (1) Symptoms | (1) Symptoms |
| (2) Treatment | (2) Treatment | (2) Treatment |
| (3) Symptoms | (3) Medication | (3) Condition |
| (4) Injury | (4) Condition | (4) Injury |
| (5) Physician | (5) Injury | |

**Table 6.** Five most frequent query types

| Inquiry | % (n=793) |
|---|---|
| (1) Seeking information about a condition | 29% |
| (2) Seeking information about treatment | 14% |
| (3) Seeking information about symptoms | 8% |
| (4) Seeking advice about symptoms | 6% |
| (5) Seeking advice about treatment | 6% |

### *Summary of Topics*

By examining the topics of the questions with the purposes of seeking information, seeking advice, or sharing information, we determined the most frequent types of queries submitted to the Web site (see Table 5 and Table 6). They were:

- Seeking information about a condition
- Seeking information about treatment
- Seeking information about symptoms
- Seeking advice about symptoms
- Seeking advice about treatment

### Relationship Between Asker and Patient

Of the 793 queries in the dataset, only 178 (22%) provided enough information for the researchers to determine the relationship between the asker and the patient. Of the 178 entries for which the relationship could be deduced, there were 140 entries (79%) in which the individual posing the question was the patient (ie, the askers were asking for themselves) and 38 entries (21%) in which the asker was clearly asking for someone else (eg, a mother, daughter, or friend).

**Table 7.** Purposes of queries by relationship with patient

| Purpose | Frequency (%) of Queries When Asker Was the Patient * † | Frequency (%) of Queries When Asker Was Friend/Relative of the Patient * † | Frequency (%) of Queries When Relationship of Asker and Patient Could Not Be Determined |
|---|---|---|---|
| Seeking advice | 96 (69%) | 20 (53%) | 77 (13%) |
| Seeking information | 25 (18%) | 17 (45%) | 516 (85%) |
| Sharing information | 16 (11%) | 1 (3%) | 5 (1%) |
| Seeking an interpretation | 4 (3%) | 1 (3%) | 7 (1%) |
| Total | 140 | 38 | 605 |

[*] The total values exceed 100% as 1 query had 2 or more purposes.

[†] Percentages do not add up correctly due to rounding.

**Table 8.** Topics about which advice was sought

| Topic | Frequency (%) of Queries Asking Advice About Specific Topics When Asker Was the Patient in Question * † | Frequency (%) of Queries Asking Advice About Specific Topics When Asker Was Relative/Friend of the Patient in Question † ‡ |
|---|---|---|
| Symptoms | 33 (34%) | 3 (15%) |
| Treatment | 22 (23%) | 8 (40%) |
| Medication | 10 (10%) | 3 (15%) |
| Condition | 9 (9%) | 2 (10%) |
| Injury | 6 (6%) | 0 |
| Physician | 5 (5%) | 2 (10%) |
| Lifestyle | 4 (4%) | 0 |
| Exercise | 3 (3%) | 1 (5%) |
| Prognosis | 3 (3%) | 1 (5%) |
| Tests/Labs | 3 (3%) | 1 (5%) |
| Diet | 2 (2%) | 0 |
| Anatomy | 1 (1%) | 0 |
| Prevention | 0 | 1 (5%) |
| Unclear | 1 (1%) | 1 (5%) |
| Total | 96 | 20 |

[*] The total values exceed 100% as 6 queries had 2 or more topics.

[†] † Percentages do not add up correctly due to rounding.

[‡] ‡ The total values exceed 100% as two queries had 2 or more topics.

Of the 140 entries in which the asker was the patient, 69% of the time the asker was seeking advice. Other purposes included seeking information (18%), sharing information (11%), and seeking an interpretation (3%) (see Table 7). Of the 96 cases in which the askers were seeking advice, the most frequent topic was symptoms (34%). Other topics included treatment (23%), medication (10%), a condition (9%), and injury (6%) (see Table 8). Of the 25 cases in which the askers were seeking information, they were most frequently inquiring about treatment (44%), symptoms (16%), a condition (12%), and exercise (8%) (see Table 9).

**Table 9.** Topics about which information was sought

| Topic | Frequency (%) of Queries Asking for Information About Specific Topics When Asker Was the Patient in Question * † | Frequency (%) of Queries Asking for Information About Specific Topics When Asker Was Relative/Friend of the Patient in Question † ‡ |
|---|---|---|
| Treatment | 11 (44%) | 3 (18%) |
| Symptoms | 4 (16%) | 1 (6%) |
| Condition | 3 (12%) | 9 (53%) |
| Exercise | 2 (8%) | 0 |
| Anatomy | 1 (4%) | 2 (12%) |
| Diagnosis | 1 (4%) | 0 |
| Diet | 1 (4%) | 0 |
| Injury | 1 (4%) | 0 |
| Lifestyle | 1 (4%) | 0 |
| Medication | 1 (4%) | 1 (6%) |
| Physician | 1 (4%) | 3 (18%) |
| Prevention | 1 (4%) | 0 |
| Support groups | 1 (4%) | 0 |
| Resources | 0 | 1 (6%) |
| Unclear | 1 (4%) | 0 |
| Total | 25 | 17 |

* The total values exceed 100% as 4 queries had 2 or more topics.

† Percentages do not add up correctly due to rounding.

‡ The total values exceed 100% as two queries had 2 or more topics.

Of the 38 entries in which the asker was a relative or friend of the patient, the 2 main purposes were seeking advice (53%) and seeking information (45%) (see Table 7). Of the 20 cases in which advice was sought, 40% were seeking advice about treatment, 15% about medication, and 15% about symptoms (see Table 8). In 17 cases, askers who were inquiring for a relative or friend were seeking information. Most frequently, they were seeking information about a condition (53%). Other frequent topics were physicians (18%), treatment (18%), and anatomy (12%) (see Table 9).

### *Summary of Relationship Between Asker and Patient*

In the cases in which the askers were submitting questions relevant to the health of their friends, their relatives, or themselves, advice was the most frequent type of query. When the relationship between the asker and the patient could not be deduced, information was the most frequent type of query. Table 10 compares the 4 most frequent types of inquiries posed by (1) askers who were the patient or relatives/friends of the patient in the question and (2) askers whose relationship to the patient could not be determined.

**Table 10.** Four most frequent types of queries by relationship

| Asker was Patient or Relative/Friend of Patient in Question | Relationship Between Asker and Patient Could Not Be Determined |
|---|---|
| (1) Seeking advice about symptoms | (1) Seeking information about a condition |
| (2) Seeking advice about treatment | (2) Seeking information about treatment |
| (3) Seeking information about treatment | (3) Seeking information about symptoms |
| (4) Seeking advice about medication | (4) Seeking information about an injury |

## Country of Origin

The queries considered in this study originated from 34 nations. Most were from the United States (647 queries, or 82%). Other countries originating a large number of queries included Australia (38 queries), the United Kingdom (34 queries), and Canada (22 queries). India and New Zealand were the source of 6 questions each, and 3 were from South Africa. Two queries originated from each of the following: Argentina, France, Germany, Ireland, Macedonia, Malaysia, Netherlands, Pakistan, Singapore, and Turkey. One query was submitted from each of the following: Belgium, Brazil, Colombia, Egypt, Hong Kong, Israel, Jamaica, Mexico, Papua New Guinea, Peru, Saudi Arabia, Spain, Sweden, Switzerland, Syria, Trinidad and Tobago, and Venezuela. Because of the relatively small number of queries from countries other than the United States, we divided the data into 2 sets: questions sent from the United States, and questions sent from all other nations.

Of the 647 queries from the United States, most were submitted for the purpose of seeking information (71%) or advice (24%) (see Table 11). Of the 458 cases in which the purpose was seeking information, 39% of the time information was sought about a condition. Other frequent topics were treatment (20%) and symptoms (11%) (see Table 12). Of the 155 cases in which the purpose was seeking advice, 30% of the questions sought advice about symptoms. Other frequent topics were treatment (23%), medication (11%), and a condition (9%) (see Table 13).

**Table 11.** Purposes of queries submitted by location of query submission

| Purpose | Frequency (%) of Queries Submitted From the United States [*] [†] | Frequency (%) of Queries Submitted From Countries Other Than the United States [†] [‡] |
|---|---|---|
| Seeking information | 458 (71%) | 118 (81%) |
| Seeking advice | 155 (24%) | 27 (19%) |
| Sharing information | 21 (3%) | 1 (1%) |
| Seeking an interpretation | 11 (2%) | 0 |
| Unclear | 4 (1%) | 1 (1%) |
| Total | 647 | 146 |

[*] The total values exceed 100% as two queries had 2 or more purposes.

[†] Percentages do not add up correctly due to rounding.

[‡] The total values exceed 100% as 1 query had 2 or more purposes.

**Table 12.** Topics about which information was sought by location of query submission

| Topic | Frequency (%) of Queries From the United States [*] [†] | Frequency (%) of Queries From Outside the United States [†] [‡] |
|---|---|---|
| Condition | 179 (39%) | 48 (41%) |
| Treatment | 92 (20%) | 22 (19%) |
| Symptoms | 51 (11%) | 13 (11%) |
| Physician | 25 (6%) | 0 |
| Injury | 24 (5%) | 6 (5%) |
| Anatomy | 18 (4%) | 6 (5%) |
| Medication | 17 (4%) | 5 (4%) |
| Tests/Labs | 12 (3%) | 2 (2%) |
| Exercise | 7 (2%) | 6 (5%) |
| Diagnosis | 5 (1%) | 1 (1%) |
| Diet | 5 (1%) | 1 (1%) |
| Resources | 4 (1%) | 1 (1%) |
| Prevention | 3 (1%) | 0 |
| Prognosis | 3 (1%) | 1 (1%) |
| Support groups | 1 (0%) | 0 |
| Lifestyle | 0 | 1 (1%) |
| Resources | 0 | 1 (1%) |
| Unclear | 25 (6%) | 8 (7%) |
| Total | 458 | 118 |

[*] The total values exceed 100% as 11 queries had 2 or more topics.

[†] Percentages do not add up correctly due to rounding.

[‡] The total values exceed 100% as 3 queries had 2 or more topics.

**Table 13.** Topics about which advice was sought by location of query submission

| Topic | Frequency (%) of Queries From the United States [*] | Frequency (%) of Queries from Outside the United States [†] |
|---|---|---|
| Symptoms | 47 (30%) | 4 (15%) |
| Treatment | 36 (23%) | 12 (44%) |
| Medication | 17 (11%) | 4 (15%) |
| Condition | 14 (9%) | 4 (15%) |
| Injury | 9 (6%) | 1 (4%) |
| Physician | 9 (6%) | 0 |
| Exercise | 8 (5%) | 1 (4%) |
| Tests/Labs | 6 (4%) | 0 |
| Prognosis | 5 (3%) | 1 (4%) |
| Lifestyle | 4 (3%) | 0 |
| Diet | 3 (2%) | 1 (4%) |
| Prevention | 1 (1%) | 0 |
| Unclear | 3 (2%) | 0 |
| Total | 155 | 27 |

[*] The total values exceed 100% as 6 queries had 2 or more topics.

[†] The total values exceed 100% as two queries had 2 or more topics.

Of the 146 submissions from all countries other than the United States, the most frequent purposes were seeking information (81%) and seeking advice (19%) (see Table 11). Of the 118 cases in which the askers were seeking information, they were most frequently asking about a condition (41%). Other frequent topics included treatment (19%) and symptoms (11%) (see Table 12). Of the 27 cases in which the askers were seeking advice, they were most often seeking advice about a treatment (44%). Other frequent topics included condition (15%), medication (15%), and symptoms (15%) (see Table 13).

### *Summary of Country of Origin*

The 3 most frequent types of inquiries submitted from the United States and from all other countries were the same (see Table 14). They were:

- Seeking information about a condition
- Seeking information about treatment
- Seeking information about symptoms

The chi-square test was used to evaluate these variables, and there were no statistically significant differences in types of questions asked based on location (Ï $^{2}_{2}$= 0.16, *P*= .92).

## Discussion

These results indicate that when people turn to the University of Washington Orthopaedics and Sports Medicine Web site with health questions, their most frequent motives are to find information about a condition, treatment, or symptoms. In our data set, conditions, treatments, and symptoms were the most frequent topics whether the purpose of the query was to seek information, seek advice, or share information. These results are similar to those of other studies suggesting that that the most frequent reasons people use the Internet for medical information are to seek information and to seek advice about topics such as conditions, treatments, and symptoms [8,10].

One similar study, conducted by Eysenbach et al, analyzed 209 unsolicited e-mails sent to physicians through a university hospital Web site, and found that 34% of the e-mails contained requests for general information about a condition or disease, while 75% of the e-mails contained specific questions, most frequently pertaining to treatment options, specialist referrals, alternative treatments, and whether a condition was curable [8]. The main topics asked by Web site users in our study were similar to those asked in Eysenbach's study. Conditions and treatments were the 2 most frequent topics in our study, while physicians and prognosis were present though less frequent (see Table 3). However, our findings differed from Eysenbach's with respect to the "purpose" of the requests: of the 793 search queries analyzed in our study, 73% were asking for information, and 23% were seeking advice (see Table 2). This variation is likely due to the different types of questions analyzed in the 2 studies. In Eysenbach's study, the objects of analysis were e-mails that patients sent to the physicians responsible for the Web site. Our study, on the other hand, analyzes questions that were submitted as a search method on a Web site, not questions that were sent in e-mail messages. Thus, we are analyzing what patients seek when they are anonymously searching a health information Web site, rather than what they seek when they make the effort to formulate a question and e-mail it to the Web site owners.

Another study with similar results as ours (but different methods) was conducted by O'Connor et al [10]. O'Connor's study investigated the information that patients of a gastroenterology clinic sought when using the Internet. By analyzing questionnaires that patients filled out when they visited the clinic, the researchers found that of the 462 patients who reported having access to the Internet, 51% had used the Internet within the last year to search for medical information. Of the patients who had utilized the Internet for medical information, 31% sought general disease information, 23% sought information about treatment options, 18% inquired about medications, 14% sought information about diet and nutrition, and 10% inquired about alternative medicine. Our results show similar trends: 32% of the queries in our study asked about a condition or disease, 21% asked about treatment, 5% asked about medications, and 1% asked about diet (see Table 3). However, because the data in O'Connor's study were derived from responses to questionnaires, their results describe what patients perceive and report about their Internet use, which may differ from their actual behavior [2,7,19]. In contrast to the study by O'Connor et al, our study examines the log files of a health information Web site to analyze the *actual* questions that Web site visitors ask, rather than relying on patients to report their behavior while at the doctor's office.

The results of our study suggest that people searching the Internet for medical information that pertains to their health (or the health of a friend or relative) may have different information needs than users searching for medical information that does not apply to their health (or the health of a friend or relative). The inquiries submitted by askers who identified themselves as the patient in question (or a friend or relative of the patient in question) did not follow the overall trend of seeking information. As shown in Table 10, when the relationship between the asker and patient could be deduced, the most frequent purpose of the inquiry was to seek *advice*, whereas when the relationship between asker and patient could not be determined, the most frequent purpose was to seek *information*.

These results also suggest that Web site visitors from around the world have similar goals when turning to the Internet for health-related information. The 3 most frequent types of inquiries submitted from the United States were not statistically different from those submitted from all other countries combined ( *P*= .92) (see Table 14). Thus, among *all* the Web site visitors from around the world, the most frequent searches performed were to seek information about a condition, treatment, or symptoms. These results indicate that the global audience of the University of Washington Orthopaedics and Sports Medicine Web site has similar information needs, regardless of geography.

**Table 14.** Three most frequent types of queries by location of submission (frequency of query)

| Query type | United States (n=647) | Countries Other Than the United States (n=146) |
|---|---|---|
| Seeking information about a condition | 179 | 48 |
| Seeking information about treatment | 92 | 22 |
| Seeking information about symptoms | 51 | 13 |

The results of this study will inform the future development, design, and content of the University of Washington Orthopaedics and Sports Medicine Web site. The Web site managers aim to improve the site's usefulness, and this data about the users' information behavior and needs will help the managers improve it specifically for the Web site's audience. It appears that the focus of the Web site is already in line with the main needs of its users, but this study has identified several areas in which user interest outstrips the Web site's coverage. First, although there are many articles about various conditions, the Web site can be improved in the areas of treatment and symptom information for orthopaedic conditions, which were the second and third most frequent topics for all types of questions. Second, "treatment" in general was the second most frequent topic asked about by users, but the Web site focuses on surgical interventions and offers few articles on nonsurgical treatments. Thirdly, the Web site does not yet provide any articles that help patients learn more about specific symptoms. Of the queries that were seeking advice, symptoms were the most frequent topic. This suggests that the articles focusing on symptoms might need to be written differently than articles about conditions or treatments (which were the most frequent topics when users sought information). Another way to respond to the findings of this study might be to redesign the Web site's user interface to reflect the topics for which the users search most often. The current design features 10 main labels: 5 body parts (eg, "shoulder & elbow") and 5 orthopaedic specialties (eg, "rheumatology"). Based on this study's findings, the Web site designers are considering changing the user interface to feature labels that are more in line with the topics for which its users search, such as "conditions," "treatments," and "symptoms." These are just a few of the ways that the Web site can be adapted to better meet the needs of its users, based on this data about what patients are really interested in learning.

This study has several possible limitations. First, the development of the coding system and the coding of the queries were performed by the same person. Krippendorf [14] suggests that it is less than ideal for the developer of a code to also be the administrator; however, he concedes that it is acceptable when resources are limited. We determined the inter-rater and intra-rater reliability measures to diminish and be aware of the possible effects of this limitation.

A second limitation is that the inter-rater reliability was determined by coding queries according to their broad topic category (refer to Table 1) rather than by specific category. Once moderate agreement was achieved with respect to the broad topic categories (eg, "condition, symptoms, and/or an injury"), the lead author went a step further to determine each query's *specific* topic (eg, "injury"). However, no inter-rater or intra-rater reliability measures were determined for this step.

A third limitation of this study pertains to the specific set of Internet users considered. Because our data consisted of questions submitted to a health education Web site focused on arthritis, orthopaedics, and sports-medicine information, most individuals submitting the questions were probably interested in information relating to these topics. Therefore, it may be difficult to use these results to make claims about how people in general use the Internet to search for any type of medical information. Moreover, this study focused on user information needs based on search queries, which excludes people who browse the Web site instead of searching it.

A fourth limitation is a common drawback of log-file analysis. When examining the IP addresses of the computers used to submit questions, we cannot know if the people who submitted the questions were actually from the countries in which their computers were operating. For example, questions from computers not based in the United States could have been American travelers or Americans who choose to live abroad, just as questions from United States-based computers could be from exchange students, travelers, or other people not from the United States. Thus, the distinction made between questions from United States-based askers and those from other countries may not have reflected the actual identity of the askers.

## Conclusions

The results of this study are important to the improvement of the University of Washington Orthopaedics and Sports Medicine Web site, as well as to the future of medical information on the Internet. With these results, the Department of Orthopaedics and Sports Medicine will be able to update and adapt its Web site based on actual users' needs. In addition, other organizations dedicated to providing online medical information can improve their Web sites' content and usefulness, based on this data about what people are seeking when they turn to the Internet for medical information. If health Web site managers can adapt their Web sites to meet their users' needs, patients may be able to find and use Internet-based health information more successfully. Finding relevant health information and support on the Internet may help people to become more actively involved in making decisions that affect their health, enabling them to participate more actively in their health care.

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Author's roles: Ms. Knight designed the coding schemes, coded the data, and wrote the first draft of the paper. Ms. Shuyler advised Ms. Knight on the research design and coding schemes, helped with literature research, and edited the paper for publication.

## Conflicts of Interest

Ms. Shuyler was funded by the University of Washington Department of Orthopaedics and Sports Medicine and the University of Washington Program for Educational Transformation Through Technology (PETTT), and was the content manager for the Web site being studied while completing this research. Currently, she is funded by the University of Washington Department Program for Educational Transformation Through Technology. Ms. Knight was funded by the University of Washington Program for Educational Transformation Through Technology. Because Ms. Shuyler was working with the Web site at the time of the research, she may have some stake in the way it is presented to the public. However, the nature of this article was to explore the information needs of our users, not evaluate the Web site itself.

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## Abbreviations

**IP:** Internet Protocol

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Original Paper

# Improving Web Searches: Case Study of Quit-Smoking Web Sites for Teenagers

Malcolm Koo[1], PhD; Harvey Skinner[1], PhD

Department of Public Health Sciences, University of Toronto, Toronto ON, Canada

**Corresponding Author:**
Malcolm Koo, PhD
Department of Public Health Sciences
Faculty of Medicine, McMurrich Building
University of Toronto
Toronto Ontario M5S 1A8
Canada
Phone: +1 416 978 6206
Fax: +1 416 978 8299
Email: m.koo@utoronto.ca

## Abstract

**Background:** The Web has become an important and influential source of health information. With the vast number of Web sites on the Internet, users often resort to popular search sites when searching for information. However, little is known about the characteristics of Web sites returned by simple Web searches for information about smoking cessation for teenagers.

**Objective:** To determine the characteristics of Web sites retrieved by search engines about smoking cessation for teenagers and how information quality correlates with the search ranking.

**Methods:** The top 30 sites returned by 4 popular search sites in response to the search terms "teen quit smoking" were examined. The information relevance and quality characteristics of these sites were evaluated by 2 raters. Objective site characteristics were obtained using a page-analysis Web site.

**Results:** Only 14 of the 30 Web sites are of direct relevance to smoking cessation for teenagers. The readability of about two-thirds of the 14 sites is below an eighth-grade school level and they ranked significantly higher (Kendall rank correlation, tau = -0.39, *P*= .05) in search-site results than sites with readability above or equal to that grade level. Sites that ranked higher were significantly associated with the presence of e-mail address for contact (tau = -0.46, *P*= .01), annotated hyperlinks to external sites (tau = -0.39, *P*= .04), and the presence of meta description tag (tau = -0.48, *P*= .002). The median link density (number of external sites that have a link to that site) of the Web pages was 6 and the maximum was 735. A higher link density was significantly associated with a higher rank (tau = -0.58, *P*= .02).

**Conclusions:** Using simple search terms on popular search sites to look for information on smoking cessation for teenagers resulted in less than half of the sites being of direct relevance. To improve search efficiency, users could supplement results obtained from simple Web searches with human-maintained Web directories and learn to refine their searches with more advanced search syntax.

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**KEYWORDS**

Internet; smoking cessation; teens; teenagers; search engines; Web page analysis

## Introduction

The World Wide Web, with over 3 million public Web sites and over 1.4 billion Web pages [1], has become an important and influential source of health information [2]. In September 2002, there were an estimated 605 million people online worldwide [3]. In the United States, 90% (48 million) of the children and adolescents between the ages of 5 and 17 use computers, and 75% of the 14 to 17 year olds use the Internet [4]. With the vast amount and dynamic nature of information on the World Wide Web, it is not surprising to find that over 75% of those online use search sites to navigate the Web [5]. However, the amount of results returned from a search is often overwhelming. For example, 115000 results were found with the search terms "teen quit smoking" in Google.

Of the several thousand search sites or directories [6], only a few are of high popularity as indicated by their audience reach and time spent on them [7]. Although Google will provide up to a thousand results from a query, few users are likely to examine them all. In an observational study on 16 adult subjects, only 9 participants ever looked beyond the first search pages and only 5 of them ever clicked a link on those pages [8]. A survey done in 2002 on 1403 e-mail participants showed that only 23% of the users went beyond the second page [9]. Another pilot study of 12 teenagers found they looked past the fourth page of results less than 5% of the time [10]. Thus, position ranking in Web-search results, especially on the first few pages, is an important determinant of information accessibility by users.

Several studies have reported substantial variability in health-related Web-site content [11- 14]. While guidelines for evaluating the quality of health information on the Web are available [15- 19], the correlation between these guidelines and accuracy of health information is debated [20- 22]. Position ranking in search results was not associated with content quality [23]. Using the search term "breast cancer," Meric et al [24] reported that popularity of Web sites was associated with type rather than quality of content. In a sample of 75 Web sites that provided information on urinary incontinence, the Internet popularity indexes—as measured by the number of links to the main incontinence page of each Web site and by the number of links to all pages of each Web site divided by the number of pages of the site—were not correlated with a quality score based on Silberg et al [16] and the HONcode principles [25].

The aim of this study was: (a) to identify the characteristics of Web sites with information on smoking cessation for teenagers that ranked in the top 30 positions in a typical Web search on popular search sites and (b) to evaluate the association between those characteristics and the position ranking for sites that are of direct relevance to smoking cessation for teenagers. The findings are relevant for improving consumer access to health information.

## Methods

This study was carried out from May 2003 through June 2003. Web sites with information on smoking cessation for teenagers were identified with 4 popular search sites using a specific search term. The characteristics of the identified sites were collected with a Web-site characteristic checklist; 2 raters evaluated each Web site independently (details below).

### Search Protocol

Four popular search sites (Table 1) were used in this study. Users spend over 5 million search hours per month at each site. A search hour equals the number of visitors to a site multiplied by the average number of hours each visitor is estimated to have spent at the site.

**Table 1.** Popular search sites in the United States*

| Search Site | URL | Total Search Hours (Millions of Hours) in January 2003 | MainUnderlying SearchEngine |
|---|---|---|---|
| Google | www.google.com | 18.7 | Google |
| AOL | search.aol.com | 15.5 | Google |
| Yahoo! | www.yahoo.com | 7.1 | Google and Overture (for paid listings) |
| MSN | search.msn.com | 5.4 | LookSmart, Inktomi, Microsoft proprietary editor, and Overture (for paid listings) |

* Source: Search Engine Watch [26].

The search term on smoking cessation for teenagers was selected based on information from the Overture Search Term Suggestion Tool [27] and the 7search Keyword Suggestion Tool [28]. These sites provide a count of the search terms that were submitted to their search engines. Overture provides their search results to various popular search sites including Yahoo, MSN, AltaVista, Lycos, HotBot, and AllTheWeb [29]. For example, in April 2003 there were 40036 searches submitted to Overture with "quit smoking," 27812 with "stop smoking," and 9001 with "smoking cessation." Various other combinations of "teen," "youth," "adolescent," "quit smoking," "stop smoking," and "smoking cessation" were compared. Based on the frequency of searches performed on the Web as recorded by the Overture database, the search terms "teen quit smoking" were submitted to the 4 search sites to locate sites with information on smoking cessation for teenagers.

To mimic the search behavior of Web users, only the top 30 search results were included in the study. Sites ranking below the top 30 results are likely to be found only by more-persistent searchers [30]. Thirty results are equivalent to 3 pages (2 clicks) of the default number of results per page in Google and AOL, 2 such pages (1 click) in MSN, and one and a half such pages (one click) in Yahoo. The results from the 4 search sites were combined into one list to provide an overall picture of the search activity on the Web. The sites were reranked by first grouping the sites into 4 groups by the number of search sites that included them (1 to 4 search sites) and then by the position ranking provided by the search results within each group. The top 30 reranked sites formed the sample for the analysis.

Since the rankings of Web sites within search-site results change frequently, the search results were captured in spreadsheet format using the Google API Search Tool [31]. The Web pages of sites identified by search results were captured using Offline Explorer software [32] to facilitate the recall of the exact page content when necessary and to provide consistency for the 2 raters.

**Table 2.** Site characteristics and correlation with search ranking for 14 sites relevant to teenagers who are seeking information on smoking cessation

| Site Characteristic | Inter-Rater Reliability (Kappa) | Characteristics | Number (%) | Kendall Rank Correlation, Tau (*P* value) |
|---|---|---|---|---|
| **Essential** | | | | |
| Search feature in the site | 0.86 | Present | 8 (57) | 0.15 (.52) |
| | | Absent | 6 (43) | |
| Site navigation system on page | 0.76 | Present | 11 (79) | -0.16 (.42) |
| | | Absent | 3 (21) | |
| Privacy statement | 0.57 | Present | 8 (57) | 0.18 (.41) |
| | | Absent | 6 (43) | |
| Disclaimer | 0.69 | Present | 9 (64) | 0.11 (.70) |
| | | Absent | 5 (36) | |
| Readability grade level | NA* | < 8.0 | 5 (36) | -0.39 (.05) |
| | | ≥ 8.0 | 9 (64) | |
| Broken links on page | NA | Present | 7 (50) | 0.08 (.75) |
| | | Absent | 7 (50) | |
| **Enhancement** | | | | |
| Indication of sponsorship | 0.19 | Present | 11 (79) | 0.09 (.66) |
| | | Absent | 3 (21) | |
| Pop-up advertisements or banner advertisements | 0.59 | Present | 4 (29) | 0.18 (.17) |
| | | Absent | 10 (71) | |
| Contact e-mail address | 0.51 | Present | 10 (71) | -0.46 (.01) |
| | | Absent | 4 (29) | |
| Phone number or mailing address | 1.00 | Present | 4 (29) | 0 (1.00) |
| | | Absent | 10 (71) | |
| Content on cessation method: behavioral approach | 0.43 | Present | 11 (79) | 0.31 (.10) |
| | | Absent | 3 (21) | |
| Content on cessation method: medication approach | 0.84 | Present | 10 (71) | -0.43 (.02) |
| | | Absent | 4 (29) | |
| Content on cessation method: alternative approach | 0.51 | Present | 5 (36) | -0.42 (.02) |
| | | Absent | 9 (64) | |
| Annotated external hyperlinks | 0.72 | Present | 5 (36) | -0.39 (.04) |
| | | Absent | 9 (64) | |
| Interactive component (quiz, game, or bulletin board) | 0.53 | Present | 8 (57) | -0.18 (.44) |
| | | Absent | 6 (43) | |
| Material in video or audio format | 1.00 | Present | 1 (7) | -0.20 (.31) |
| | | Absent | 13 (93) | |
| **Technical** | | | | |
| Page size (kilobyte) | NA | < 35 | 6 (43) | -0.39 (.04) |
| | | ≥ 35 | 8 (57) | |
| Meta description tag | NA | Present | 8 (57) | -0.48 (.002) |

| Site Characteristic | Inter-Rater Reliability (Kappa) | Characteristics | Number (%) | Kendall Rank Correlation, Tau (*P* value) |
|---|---|---|---|---|
| | | Absent | 6 (43) | |
| Meta keywords tag | NA | Present | 11 (79) | -0.31 (.13) |
| | | Absent | 3 (21) | |
| Persistent cookies | NA | Present | 3 (21) | -0.34 (.06) |
| | | Absent | 11 (79) | |
| Part of a larger Web site | 0.72 | Yes | 6 (43) | 0.03 (.90) |
| | | No | 8 (57) | |
| Link density (reverse links) | NA | 1 | 6 (43) | -0.58 (.02) |
| | | 2-100 | 4 (29) | |
| | | > 100 | 4 (29) | |

[*] NA = Not applicable. Kappa values for these characteristics were not available because they were analyzed by the WebXact Watchfire Page Analysis [35], except for readability grade level which was evaluated by only 1 rater.

### Checklist of Web-Site Characteristics

A checklist was uses to evaluate the characteristics of the Web sites (see Table 2 for checklist items). The readability was estimated by the Flesch-Kincaid grade-level score [33]. (The Flesch-Kincaid grade-level score rates text on a United States grade-school level. For example, a score of 8.0 means that an eighth grader can understand the document.) Sample passages from the Web pages with information pertaining to smoking cessation of the identified sites were pasted into Microsoft Word XP for Windows to obtain the score. The results were recorded in a spreadsheet and subsequently imported into SPSS [34] for analysis. The number of broken links, page size, presence of meta tags, and presence of persistent cookies were obtained from WebXact Watchfire Page Analysis [35]. (Meta tags are HTML [hypertext markup language] tags that provide information about the content of a Web page for indexing by search engines but do not affect how a Web page is displayed by a browser.) Link density was obtained by using a reverse-lookup query (link:siteURL, where *siteURL* is replaced by the Web site's URL) in Google. The link density of a site is the number of external sites that have a link to that site. A site with a higher link density is generally more likely to be found by visitors because they may find it through the external sites.

### Statistical Analysis

Correlations between position ranking and the Web-site characteristics were calculated using the Kendall rank correlation. The value of the coefficient (tau) ranges from -1 to 1. A value of zero indicates no correlation, values near 1 indicate a strong direct correlation, and values near -1 indicate a strong inverse correlation. Interobserver reliability between the 2 raters was calculated using Kappa statistics on all variables except readability, link density, and those returned by WebXact Watchfire Page Analysis. We regarded *P*£ .05 as statistically significant.

## Results

Of the top 30 sites identified by the 4 search sites using the search terms "teen quit smoking," only 14 were relevant to teenagers who are seeking information on smoking cessation. We also evaluated the search results from Google by using other similar search terms. The number of relevant sites ranged from 5 to 17 (Table 3). Although we used only 1 search site to illustrate the effect of search terms on the type of Web sites found, the result should be similar at other search sites.

### Characteristics of the 14 Relevant Web Sites

The characteristics of the 14 sites are summarized in 3 categories (Table 2).

### *Essential-Characteristic Category*

The essential-characteristic category contains those characteristics that contribute to user dissatisfaction if absent or inadequately provided. The presence of a privacy statement and disclaimer, although it appears not to be required for the functioning of a Web site, wasreported to be essential in a Web-user interface study [36].

The correlation between the 2 raters ranged from 1.00 for 2 characteristics (presence of phone number or mailing address and presence of material in video or audio format) to 0.19 for indication of sponsorship. The median correlation was 0.69 for the 15 characteristics evaluated by both raters.

In the essential category, 8 sites (57%) contained a site-search feature and 11 sites (79%) contained links for navigation in the site. However, 2 sites contained neither of the features. Over half of the sites contained either a privacy statement (57%) or a disclaimer (64%) but only a third of the sites contained both. About one-third of the sites have readability below eighth-grade school level and they ranked significantly higher (tau = -0.39, *P*= .05) than those that have readability above or equal to that level. The median grade level was 8.5. Half the sites contained one or more broken internal or external hyperlinks.

### *Enhancement-Characteristic Category*

In the enhancement-characteristic category, 11 sites (79%) indicated their sponsorship. Apparently because most of the sites were sponsored by organizations, government bodies, or educational institutions, only 4 sites (29%) had either pop-up advertisements or in-page banner advertisements. E-mail address

(71%) was the most-common contact information available while phone number or mailing address was present in 29% of the sites. Sites that ranked higher were significantly associated with the presence of e-mail address for contact (tau = -0.46, *P*= .01). Eleven sites (79%) had information on behavioral approach as a method of smoking cessation. Ten sites (71%) had information on a medication (nicotine replacement) approach, and 5 sites (36%) had information on alternative approaches such as acupuncture, hypnosis, laser therapy, and herbal cigarettes. Both the presence of medication (tau = -0.43, *P*= .02) and alternative approaches (tau = -0.42, *P*= .02) were significantly associated with a higher search ranking. Five sites provided annotated hyperlinks to external sites and their presence was significantly associated with a higher search ranking (tau = -0.39, *P*= .04). Eight sites contained interactive components such as quizzes, games, or bulletin boards. Only 1 site provided material in video or audio format.

**Table 3.** Type of Web sites found with different search terms using Google search site

| **Type of Web Site** | **Search Terms Used** | | | | |
|---|---|---|---|---|---|
| | teen quit smoking | teen stop smoking | teen smoking cessation | youth quit smoking | adolescent quit smoking |
| Site with information to help teenagers quit smoking | 14 | 5 | 5 | 17 | 5 |
| Page with hyperlinks to Web sites with information to help teenagers quit smoking | 3 | 1 | 5 | 3 | 4 |
| News or press release | 4 | 5 | 3 | 3 | 5 |
| Report of study results or proceedings from conferences | 1 | 2 | 5 | 2 | 9 |
| Recruitment of study subjects | 2 | 1 | 1 | 0 | 0 |
| Commercial site | 3<br>(2 were redirects*) | 4<br>(1 was a redirect) | 0 | 0 | 2<br>(both redirects) |
| Site for teenagers but not on smoking | 1 | 2 | 0 | 0 | 0 |
| Resources on teenager smoking cessation for parents or health professionals | 1 | 4 | 5 | 3 | 2 |
| Health organizations or community centers | 0 | 1 | 3 | 1 | 1 |
| Page not found | 1 | 4 | 2 | 1 | 0 |
| Other | 0 | 1<br>(alt.support.stop-smoking Usenet archive) | 1<br>(porno-graphic Web site) | 0 | 2<br>(mental health Web site) |

[*] The visitor was automatically sent to a page other than the page listed in the search results (see Discussion for details).

### *Technical-Characteristic Category*

In the technical-characteristic category, the largest file size of the landing page (the page reached when clicking on the search-site result) was 134 kilobytes, which is equivalent to approximately 19 seconds of download time on a 56 Kbps modem. Sites that were equal to or larger than 35 kilobytes (57%) were ranked significantly higher (tau = -0.39, *P*= .04) by the search sites. Eight (57%) and 11 (79%) of the sites had meta description and meta keywords tags, respectively. The presence of a meta description tag was significantly associated with a higher search rank (tau = -0.48, *P*= .002). Although 5 sites used cookies (small files sent to the browser along with a Web page for tracking a visit), only 3 of them used a persistent cookie that is stored on the user's hard disk and 4 used a session cookie that is automatically deleted from the browser's cache when the browseris closed. Six (43%) sites were just part of larger Web sites containing information other than smoking. The median link density of the 14 Web pages was 6 and the maximum was 735. A higher link density was significantly associated with a higher search rank (tau = -0.58, *P*= .02).

## Discussion

The key finding of this study was that using simple search terms on popular search sites to look for information on smoking cessation for teenagers, less than half (14 of 30) of the sites found were of direct relevance. The remaining sites were study reports, news, and hyperlinks.

We did not include all information retrieved from Web searches, as has been done in studies on other topics [37], since users tend not to go beyond the first few pages of search results [9,10]. Instead, we evaluated only the top 30 search results to mimic typical Web search behavior.

Searching with the terms "teen quit smoking" on 7 popular search sites, Edwards et al [38] also reported that only 40% of the 140 potential hits were focused on cessation. In our study, 1 site of pornographic nature was found when using the search terms "teen smoking cessation" but no such sites were found when using the search terms "teen quit smoking" in contrast to a previous report [39] where 7 out of the top 20 sites were teen pornography sites.

Of public health concern was the finding that 3 sites were commercial sites and 2 of them were linked back to a single online drug store using a page-redirect spamming technique. With page redirection, an optimized page with unique and specific terms is submitted to search sites with the single purpose of ranking high on a specific topic. However, anyone clicking the link to this page is automatically sent to a real destination page, which often contains material unrelated to the initial search terms. For example, one site used "what-happens-to-your-body-when-you-quit-smoking.htm" as the name of its Web page. However, this page contains no information on smoking cessation. Instead, it is a page with a JavaScript that immediately redirects visitors to an online drug store.

Several important associations were found between Web-site characteristics and position ranking in the top 30 search results. These results can be used for optimizing site development in future smoking-cessation Web sites.

## Essential-Characteristic Category

As an example of how these results can be used, of the 6 items in the essential-characteristic category, readability (lower grade level) was associated with higher position ranking. The lack of search box, navigational menu, privacy statement, or disclaimer, or the presence of broken links, was not uncommon, but their absence was not associated with lower position ranking.

## Enhancement-Characteristic Category

In the enhancement-characteristic category, presence of contact e-mail address, medication-cessation information, alternative-approach information, and annotated external links were associated with higher position ranking. It is surprising to find that only 1 site displayed a HONcode insignia which, along with the associated membership, is an indication that a site complies with an 8-point code of conduct put forth by Health on the Net [18]. Although 73% of young people said that knowing who produced health information is very important to them, only 29% of those who looked up health information online checked the source the last time they conducted a search [5] and it is likely that fewer will check for the authenticity (for example, verify the membership status of a site at the HON Web site) of any indications of external recognition even if they are present [8].

## Technical-Characteristic Category

In the technical-characteristic category, page size that was larger than 35 kilobytes, presence of a meta description tag, and a high link density were associated with higher ranking. The strong association between site description meta tag and ranking (tau = -0.48, *P*= .002) suggests that such information is relevant to the ranking algorithms of the search-engines used. Including a concise description tag is likely to be more effective in improving search-engine visibility than just a comprehensive keywords list. In fact, due to high rate of keyword repetition and spam, search sites such as Google and AltaVista do not give consideration to the keywords meta tag in their ranking [40,41]. As expected, link density is strongly associated with ranking (tau = -0.58, *P*= .02). Search engines generally use the number of incoming links (link density) in their ranking algorithm. However, Google's PageRank algorithm also takes into account the number of outgoing links on the page of each of the incoming links [42].Therefore, to achieve a high ranking a Web site should try to get listed on as many sites as possible and, in particular, on those sites that have as few external links as possible. Since search engines assign higher ranking to sites with incoming links that originate from pages containing fewer external links, and sites with annotated external links tend to have fewer links than those sites without annotated external links, this may explain the association between the presence of annotated external links and higher ranking (tau = -0.39, *P*= .04).

To improve search efficiency, users may want to supplement results from search sites with those from subject-based Web directories that are created and maintained by people, rather than by algorithms, such as Yahoo! Directory, which has a teen-smoking section [43]. Using the Yahoo! directory, we found 25 sites listed, of which only 4 were found using our search terms at the 4 popular search sites. In addition, users may want to learn and apply the specific syntax of their favorite search sites when searching for information. For example, quit-smoking Web sites of the commercial (.com) domain can be eliminated from the search results by entering "quit smoking -site:.com" in the search box in Google.

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## Conflicts of Interest

None declared.

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Original Paper

# Searching for Cancer Information on the Internet: Analyzing Natural Language Search Queries

Judith L Bader[1], MD; Mary Frances Theofanos[1], MS

National Cancer Institute, Office of Communications, Cancer Information Products and Services, Communications Technology Branch, Bethesda MD, USA

**Corresponding Author:**
Judith L Bader, MD
Communications Technology Branch
National Cancer Institute
6116 Executive Blvd, Suite 3048A
Bethesda MD 20852
USA
Phone: +1 301 594 3382
Fax: +1 301 435 6069
Email: jbader@mail.nih.gov

## Abstract

**Background:** Searching for health information is one of the most-common tasks performed by Internet users. Many users begin searching on popular search engines rather than on prominent health information sites. We know that many visitors to our (National Cancer Institute) Web site, cancer.gov, arrive via links in search engine result.

**Objective:** To learn more about the specific needs of our general-public users, we wanted to understand what lay users really wanted to know about cancer, how they phrased their questions, and how much detail they used.

**Methods:** The National Cancer Institute partnered with AskJeeves, Inc to develop a methodology to capture, sample, and analyze 3 months of cancer-related queries on the Ask.com Web site, a prominent United States consumer search engine, which receives over 35 million queries per week. Using a benchmark set of 500 terms and word roots supplied by the National Cancer Institute, AskJeeves identified a test sample of cancer queries for 1 week in August 2001. From these 500 terms only 37 appeared ≥ 5 times/day over the trial test week in 17208 queries. Using these 37 terms, 204165 instances of cancer queries were found in the Ask.com query logs for the actual test period of June-August 2001. Of these, 7500 individual user questions were randomly selected for detailed analysis and assigned to appropriate categories. The exact language of sample queries is presented.

**Results:** Considering multiples of the same questions, the sample of 7500 individual user queries represented 76077 queries (37% of the total 3-month pool). Overall 78.37% of sampled Cancer queries asked about 14 specific cancer types. Within each cancer type, queries were sorted into appropriate subcategories including at least the following: General Information, Symptoms, Diagnosis and Testing, Treatment, Statistics, Definition, and Cause/Risk/Link. The most-common specific cancer types mentioned in queries were Digestive/Gastrointestinal/Bowel (15.0%), Breast (11.7%), Skin (11.3%), and Genitourinary (10.5%). Additional subcategories of queries about specific cancer types varied, depending on user input. Queries that were not specific to a cancer type were also tracked and categorized.

**Conclusions:** Natural-language searching affords users the opportunity to fully express their information needs and can aid users naïve to the content and vocabulary. The specific queries analyzed for this study reflect news and research studies reported during the study dates and would surely change with different study dates. Analyzing queries from search engines represents one way of knowing what kinds of content to provide to users of a given Web site. Users ask questions using whole sentences and keywords, often misspelling words. Providing the option for natural-language searching does not obviate the need for good information architecture, usability engineering, and user testing in order to optimize user experience.

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**KEYWORDS**

Cancer; Internet; search engines; natural language processing

## Introduction

For members of the general public who use the Internet, many seek medical information [1- 6]. According to a recent systematic review of 24 peer-reviewed publications describing the proportions of Internet users among various populations of cancer patients in the developed world, about 39% of cancer patients are using the Internet directly, and in addition, 15% to 20% of persons with cancer use the Internet "indirectly" through family and friends [7]. Studies have evaluated information-seeking behavior on the Internet by cancer patients generally [8- 10], their companions [11,12], and patients with the following common specific cancer diagnoses: breast [13-16], prostate [17,18], lung [19], and gastrointestinal cancers [20]. Studies have also evaluated information gathering by cancer patients undergoing radiotherapy [21] and chemotherapy [22], and those from centers outside of North America [23,24]. Individuals from certain disadvantaged groups have been shown to seek medical information online less frequently and with more difficulty [7,25,26].

Eysenbach and Kohler found that general consumers search for medical content using search engines rather than medical portals or sites of medical societies or libraries [27]. Newly-diagnosed cancer patients and their families often start their searches as users less sophisticated in Web and medical terminology. They too commonly begin searching on popular search engines rather than on prominent cancer-information sites. We know that many visitors to our own Web site [28] arrive via search engine result links.

To better understand users' needs this research aimed to establish what lay users really want to know when they search online for cancer information. To do this we evaluated data from Ask.com [29], a popular natural-language-processing (NLP) search engine. Natural-language-processing search engines allow users to create queries using whole phrases and sentences of any length, rather than just key words.

Earlier reports of this project have been published in abstract form only. The abstracts reported a brief project summary [30], and data specific for breast cancer [31] and gastrointestinal cancer [20]. This is the first comprehensive report of the entire project.

## Methods

The National Cancer Institute (NCI) partnered with AskJeeves, Inc to develop a methodology to capture, sample, and analyze 3 months of cancer-related queries on the Ask.com Web site, a prominent US natural-language-processing consumer search engine. At the time of the project, Ask.com was receiving over 35 million queries per month.

### Search Terms

An NCI oncologist (JLB) developed a benchmark set of 500 terms and word roots that were matched against actual AskJeeves user queries. Most terms and word roots were from the NCI dictionary on the NCI Web site [32]. NCI also suggested additional terms not included in the dictionary. These terms related to anatomy, organ systems, treatments, pharmaceuticals, treatment and diagnostic procedures, genetics, epidemiology, and pathology.

**Table 1.** Top 37 search terms and roots with ≥ 5 queries per week during test week

| Term | Actual Queries During Test Week | % of Total Queries |
|---|---|---|
| *cancer* | 9765 | 56.75 |
| *tumor* | 1396 | 8.11 |
| *carcino* | 656 | 3.81 |
| *leukemia* | 635 | 3.69 |
| lymphom* | 419 | 2.43 |
| chemotherapy | 378 | 2.20 |
| biopsy/biopsies | 375 | 2.18 |
| *melano* | 348 | 2.02 |
| *sarcoma* | 294 | 1.71 |
| *dysplasia* | 255 | 1.48 |
| hodgkin* | 245 | 1.42 |
| MRI | 214 | 1.24 |
| clinical trial | 187 | 1.09 |
| mammogr | 175 | 1.02 |
| maligna* | 170 | 0.99 |
| *metasta* | 155 | 0.90 |

"*" is a placeholder for the part of the search term before or after the root.

The test sample of these 500 words and roots was used to filter cancer queries from the Ask.com Web site for 1 week in August 2001. From these 500 terms, only 37 appeared ≥ 5 times per day over the trial week. The list of 37 terms (plus common misspellings) yielded 17208 queries for the test week. The frequency of each term is shown in Table 1. Queries with common misspellings, (eg, prostate and prostrate, biopsy and biopsey, leukemia and lukemia, chemotherapy and chemothereapy) were captured and analyzed. It was felt that the cut off of 5 times per day (≥ 35 times per week) would capture the key queries and include any common query topic, since even with a frequency of 35 queries a week, the majority of these terms accounted for less than 1% of the total population. Of the original 500 terms supplied by NCI, only 7% (35/500) appeared in the logs at a high frequency, but this 7% accounts for over 37% of user queries identified as cancer related on Ask.com during the study period.

## Collecting Queries and Sampling

The process used for collecting and sampling queries is outlined in Figure 1. Using the 37 terms to search the Ask.com query logs, 204165 instances of cancer-related queries were found for June, July, and August 2001. Of these queries, 7500 individual user questions were randomly selected by AskJeeves for detailed analysis (see Appendix 1).

**Figure 1.** Processing of cancer queries on Ask.com

Very often there were multiples of the same questions. Thus, these 7500 queries actually represented 76077 queries that were entered into Ask.com, about 37% (76077/204164) of all queries identified as cancer-related from the 3 month period of log analysis. For example, a user question might be "Where can I find information about breast cancer?" This individual example represents 1 user question, but might have been queried by more than 100 people on any given day. Each query was counted only once.

## Sampling Issues

The random sample of 7500 individual queries provides a confidence interval of 1.11% at a confidence level of 95%. This means that even if more samples were taken from 204165 queries, 95% of those samples should not be off by more than 1.1%. While this means that the samples themselves would not vary more than 1.1% over 95% of the samples taken, as the data are categorized and classified, in effect smaller and smaller samples are taken. Therefore, to offset this problem additional queries were examined, even though a smaller sample would still provide a high degree of confidence in the results.

In other words, although broad generalizations—such as "breast cancer accounts for 25% of all cancer queries"—can be easily presented, a large sample size is required to break down data far enough to conclude that when users ask about breast cancer, they are most often asking about specific types of treatments.

## Highest-Level Categories for Queries

User queries were assigned to a set of 6 highest-level categories (as shown in Table 2):

- Cancer (ie, specifically mentioning a cancer type)
- General Research
- Treatment
- Diagnosis and Testing
- Cause/Risk/Link
- Coping

**Table 2.** Highest-level categories for queries

| Highest-Level Category | Number of Queries | Percent of All Sampled Queries [*] |
|---|---|---|
| Cancer [†] | 59619 | 78.37 |
| General Research | 7808 | 10.26 |
| Treatment | 3832 | 5.04 |
| Diagnosis and Testing | 3315 | 4.36 |
| Cause/Risk/Link | 1249 | 1.64 |
| Coping | 254 | 0.33 |
| **Total** | **76077** | |

[*] Percentages do not sum to 100% due to rounding.

[†] ie, specifically mentioning a cancer type.

Highest-level categories were created in a collaborative effort between the AskJeeves data-analysis team and NCI staff before the study period began, but the final category titles were revised as the actual queries were analyzed. The initial categories were based on user queries entered into Ask.com and a variety of online sources, such as NCI's online dictionary [32] and NCI's Physician Data Query (PDQ) [33].

The highest-level categories were populated using proprietary AskJeeves filters and automated-analysis tools that sorted queries according to specific types of cancers, or—in the absence of mentioning a specific cancer type—whether the query asked about other areas such as Treatment or Coping. (AskJeeves did not share the filters and automated analysis tools with the authors.) Queries that could not be sorted by the filters and automated-analysis tools were placed in a temporarily-uncategorized category; they were categorized during the next step (reading and analysis).

Reading and analyzing each individual query not only verified the automated process, but also helped to refine existing categories and create new categories and subcategories, as appropriate. For example, without this type of analysis, the query "Where can I find a Web site with information on using high protein food to fight Breast cancer?" might have been left under Breast Cancer > Media and Organizations > Web sites (where ">" indicates a change in category level). This would not be correct, as the true user intent was to inquire about Alternative Treatments. As a result, under the category Breast Cancer > Treatment, "Alternative" was added to the Breast Cancer > Treatment category analysis as a subtopic. (Treatment—without a specific cancer site designated—is both a highest-level category and a subcategory under Breast Cancer and under most cancer types.)

Approximately 78% of all categorized queries from the sample referenced a particular type of Cancer, and were placed in the highest-level category Cancer. An example of this kind of query would be "Where can I find information about Breast Cancer?" (This query would be classified as Cancer > Breast Cancer > General Information.) Any query that did not mention a specific kind of Cancer, even though the question was about cancer, was placed on 1 of the 5 other highest-level categories. An example of this type of query would be "Where can I find information on cancer treatment with radiation?" This query was assigned to the Radiation subcategory in the highest-level category Treatment (ie, it was classified as Treatment > Radiation).

Queries that did not relate to a specific Cancer type were placed in 1 of the 5 other highest-level categories: General Research, Treatment, Diagnosis and Testing, Cause/Risk/Link, or Coping. For example the query "How does smoking cause cancer?" would be placed in the Cause/Risk/Link category, as it did not refer to any specific type of cancer.

### "Cancer" Queries (Related to Specific Cancer Types)

As shown in Table 3, there were 14 cancer types (N = 59619 queries) selected as subcategories of the Cancer highest-level category. For cancer types with the most-frequent queries, like Digestive/Gastrointestinal/Bowel (D/G/B), Breast, and Genitourinary, there were enough queries to populate standard subcategories like General Information, Treatment, Symptoms, Diagnosis and Testing, and Cause/Risk/Link. These common cancer types often warranted the creation of customized subcategories, like Breast > Media and Organizations > Web sites. For the less-common cancer type queries, like Bile (duct) in D/G/B, few queries were received and only those in General Information are shown.

**Table 3.** Cancer types

| Type within Top-Level Cancer Category | Number of Queries | % Queries in Cancer Category * † | % Queries in This Report * ‡ |
|---|---|---|---|
| Digestive/Gastrointestinal/Bowel (D/G/B) | 8959 | 15.0 | 11.8 |
| Breast | 6953 | 11.7 | 9.1 |
| Skin | 6709 | 11.3 | 8.8 |
| Genitourinary | 6250 | 10.5 | 8.2 |
| Hematologic/Blood | 5448 | 9.2 | 7.2 |
| Gynecological | 5344 | 9.0 | 7.0 |
| Lung | 4630 | 7.8 | 6.1 |
| Soft Tissue/Muscle | 3954 | 6.6 | 5.2 |
| Lymphoma | 3333 | 5.6 | 4.4 |
| Head and Neck | 2522 | 4.2 | 3.3 |
| Brain/Neurological | 1852 | 3.1 | 2.4 |
| Miscellaneous Cancer | 1633 | 2.7 | 2.1 |
| Bone | 1429 | 2.4 | 1.9 |
| Pediatric | 603 | 1.0 | 0.8 |

[*] Percentages do not sum to 100% due to rounding.

[†] Denominator (N = 59619) was the total number of queries about specific types in the Cancer category.

[‡] Denominator (N = 76077) was the total number of queries analyzed in this report.

### Privacy Issues

Although NCI helped create the search terms and the categories into which the analyzed data was placed, NCI did not have access to: the raw query logs at AskJeeves, any information about what AskJeeves users did with the searches generated on the AskJeeves Web site (ie, what links they picked), or the identities of any users of the Ask.com Web site. NCI did not require permission from the Institutional Review Board.

## Results

### Frequency of Top-Level Categories

As shown in Table 2, The 6 highest-level categories in order of decreasing frequency of queries were:

- Cancer (N = 59619, 78.37%)
- General Research (N = 7808, 10.26%)
- Treatment (N = 3832, 5.04%)
- Diagnosis and Testing (N = 3315, 4.36%)
- Cause/Risk/Link (N = 1249, 1.64%)
- Coping (N = 254, 0.33%)

The data in Table 2 indicate that the great majority of users asked for information about specific types of cancers, but rarely asked about a Treatment option or Diagnosis and Testing procedure without specifying the particular cancer about which they were concerned. Similarly, users asked few queries about general Symptoms of cancer unrelated to a specific type of cancer (see Diagnosis and Testing > Symptoms, N = 473, 14.27%). An example would be "what are some symptoms of cancer?"

### Subdividing Cancer Queries

Table 3 breaks down the highest-level category Cancer queries (N= 59619) into more specific cancer types. In order of decreasing frequency within the Cancer category, the 14 subcategories were:

- Digestive/Gastrointestinal/Bowel (D/G/B) (N = 8959, 15.0%)
- Breast (N = 6953, 11.7%)
- Skin (N = 6709, 11.3%)
- Genitourinary (N = 6250, 10.5%)
- Hematologic/Blood (N = 5448, 9.2%)
- Gynecological (N = 5344, 9.0%)
- Lung (N = 4630, 7.8%)
- Soft Tissue/Muscle (N = 3954, 6.6%)
- Lymphoma (N = 3333, 5.6%)
- Head and Neck (N = 2522, 4.2%)
- Brain and Neurological (N = 1852, 3.1%)
- Miscellaneous (N = 1633, 2.7%)
- Bone (N = 1429, 2.4%)
- Pediatric (N = 603, 1.0%)

Any query specifically mentioning a cancer type by name, was assigned to that subcategory. For example, questions about Breast-Cancer-specific Treatment, Diagnosis and Testing, Causes, and Coping are found in the Cancer > Breast Cancer category, within 1 of the 10 subcategories displaying Breast Cancer information. All questions about Leukemia or Myeloma would be found in Hematologic/Blood, Hodgkin's Disease queries in Lymphoma, and Esophageal cancer questions in D/G/B.

The number of subcategories assigned to each of the 14 different cancer types varied somewhat and was driven by the nature and number of the specific queries in those cancer types.

### Detailed Analysis of Queries

The detailed categorizations and verbatim display of examples of sampled queries are shown in Appendix 1. There is a breakdown of all the 14 cancer types within the highest-level category Cancer as well as a breakdown of queries within the 5 other highest-level categories not referencing any particular cancer type. These 19 are arranged alphabetically in the Appendix.

Major observations about the 19 categories and subcategories are noted below, in the order they appear in the Appendix. Our comments emphasize issues related to requested cancer content more than technology issues related to the natural language processing.

#### *1.0 Bone Cancer*

As shown in Appendix 1, there were 1429 queries about Bone Cancer. The vast majority of Bone Cancer queries asked for General Information (N = 1107, 78%). An example of this category would be: "Where is information on bone cancer?" Users asked questions about Bone Cancers linked to various sites of Anatomy as well as certain Histologies. There were some questions related to Bone Cancers in teenagers that were assigned to this category, rather than the Pediatric category. There were more questions about Diagnosis and Testing (N = 64, 4.48%) and Symptoms (N = 135, 9.45%) than Treatment (N = 26, 1.82%).

#### *2.0 Brain and Neurological Cancer*

Of the 1852 Brain and Neurological Cancers queries, General Information accounted for the vast majority (N = 1323, 71.44%). There were 427 (23.1%) questions about specific cancer types in this category. Some cancer types queries asked about Medulloblastoma, which is typically but not always a Pediatric tumor. As with Bone Cancer above, some questions could have been meaningfully assigned to more than 1 top-level Cancer site category. In this category there were more queries about Symptoms (N = 259, 13.98%) than Treatment (N = 112, 6.05%).

#### *3.0 Breast Cancer*

As Shown in Appendix 1, Breast Cancer was one of the simpler cancer types, from a data-display standpoint. There was only 1 anatomic-cancer type and all of the individual queries for that cancer type were assigned into 1 of 10 subcategories.

The 10 top-level Breast Cancer subcategories were:

- General Information (N = 3423, 49.23%)
- Symptoms (N = 889, 12.79%)
- Treatment (N = 570, 8.20%)
- Media/Organization (N = 428, 6.16%)
- Cause/Risk/Link (N = 393, 5.65%)
- Diagnosis and Testing (N = 376, 5.41%)
- Statistics (N = 274, 3.94%)
- Pictures (N = 225, 3.24%)
- Type (N = 217, 3.12%)
- Definition (N = 158, 2.27%)

Nine of the 10 Breast Cancer subcategories were analyzed in detail in Appendix 1. The tenth, Pictures, did not require further analysis. Most queries asked for General Information.

There were more frequent queries about Breast Cancer (N = 6953) than any other cancer type. This may not be apparent from Table 3, which appears to show more D/G/B cancers (N = 8959). However, D/G/B overall is actually composed of 10 cancer types. The most frequently queried cancer type in D/G/B was Colorectal (N = 4,801) which had fewer queries than Breast.

Even though other cancer types may have been assigned more subcategories than the 10 for Breast, the detail and the medical specificity and technical vocabulary of Breast queries appear to be the most complex than other Cancer sites, probably reflecting the sophistication of basic research and clinical data on this topic and the relative sophistication of the breast cancer information seekers.

### *4.0 Cause and Risk*

There were 1249 queries in this highest-level category. Without mentioning a specific cancer by name, there were N = 1115 (89.27%) queries about Causes and Links but only N = 134 (10.73%) about Prevention. Among the 1115 queries in the Causes and Links subcategory, the following topics were noted:

- Drugs (N = 287, 25.74%)
- Unspecified (N = 247, 22.15%) (eg, "What is cause a cancer?" [sic])
- Radiation (N = 247, 22.15%)
- Personal (N = 116, 10.40) (eg, "Can anti-persperant [sic] deodorant cause cancer?")
- Chemical/Plastics (N = 74, 6.64%)
- Environmental (N = 70, 6.28%)
- Food Supplement (N = 64, 5.74%)
- Genetic Mutation/Virus (N = 10, 0.90%)

Smoking was not in this list, probably because most queries about smoking were included under a query about a specific type of cancer, like Lung or Head and Neck.

### *5.0 Coping*

There were only 254 queries about Coping. The queries referenced Support Groups (N = 127, 50%), Pain (N= 98, 38.58%), and Depression (N = 29, 11.42%). Even though there were few questions in this highest-level category, the issue was of specific interest to NCI, which asked for this category to be created and analyzed separately.

### *6.0 Diagnosis and Testing*

There were 3315 queries in this highest-level category, which did not mention a specific cancer by name. Most were queries about specific Testing (N = 2842, 85.73%). The others (N = 473, 14.27%) were queries about Symptoms. Among Testing queries, CAT/CT scan (Computerized Axial Tomography/Computed Tomography scan) (N = 1509, 53.10%) and MRI (N = 587, 20.65%) were the most-common Testing topics, followed by Biopsy (N = 502, 17.66%).

### *7.0 Digestive/Gastrointestinal/Bowel (D/G/B)*

The presentation of data queries for D/G/B in Appendix 1 is complex because, there were 7 top-level subcategories, including General Information and 10 cancer types identified in the General Information subcategory

As shown in Appendix 1, 8959 queries for D/G/B sites were broken down into 7 subcategories:

- General Information (N = 5568, 62.15%)
- Symptoms (N = 1506, 16.81%)
- Diagnosis and Testing (N = 1125, 12.56%)
- Treatment (N = 294, 3.28%)
- Statistics (N = 184, 2.05%)
- Definition (N = 163, 1.82%)
- Cause/Risk/Link (N = 119, 1.33%)

Most queries asked for General Information. Examples of General Information queries would be "Where can I learn about the cancer esophageal cancer?"? and "Where can I find information on Stomach cancer"?

A breakdown of all D/G/B queries by cancer type is shown in the list below. The absolute numbers and percentages (of all D/G/B queries) in the list below differ from the pie diagram in Appendix 1 because the list below includes organ-type queries from General Information plus the 6 other subcategories in D/G/B.

- Colorectal (N = 4801, 53.59)
- Liver (N = 1413, 15.77%)
- Gastrointestinal (stomach) (N = 1094, 12.21%)
- Pancreas (N = 965, 10.77%)
- Bowel (N = 273, 3.05%)
- Esophagus (N = 260, 2.90%)
- Other (N = 153, 1.7%)

The organ subsites in Other include Gall Bladder, Bile Duct, Anal, and Abdominal.

As noted in Appendix 1, for D/G/B there were far more questions about Symptoms (N = 1506, 16.81%) than Treatment (N = 294, 3.28%) possibly reflecting the fact that (1) users of Ask.com were just beginning their D/G/B information seeking and (2) there is less complexity in the published Treatment data for D/G/B compared to some other cancer types, like Breast Cancer.

The terms Bowel, Gastrointestinal, Stomach, and Abdominal may have been used interchangeably by users. They appear not to recognize that queries for sigmoid, rectum, cecum, appendix, transverse colon, small bowel, and stomach (gastric) cancer would provide much more useful information.

For D/G/B, some queries about Liver Metastases were included with queries about primary Liver Cancers.

### *8.0 General Research*

There were 7808 queries assigned to the highest-level category General Research, a topic not linked to a specific cancer type. In this category the 5 most-common subcategories were:

- Research (N = 2819, 36.10%)
- Organization (N = 1656, 21.21%)
- Clinical Trials (N = 1272, 16.29%)
- Concerns (N = 1201, 15.38%)
- Pictures (N = 559, 7.16%)

Among the queries about Organization, there were 1065 queries about the American Cancer Society (ACS) and 223 about the National Cancer Institute (NCI).

Among the 1272 queries about Clinical Trials, the most-common 3 questions/topics were:

- What are ... (N = 634, 49.84%) eg, "What are clinical trials?"
- Latest ... (N = 260, 20.44%) eg, "latest cancer clinical trial research"
- Types of ... (N = 111, 8.73%) eg, "types of cancer trials"

### 9.0 Genitourinary Cancers

In decreasing order, the frequency of Genitourinary organ-type queries (N = 6250) in all 12 Genitourinary subcategories including General Information was:

- Prostate (N = 3141, 50.26%)
- Testicular (N = 1772, 28.35%)
- Bladder (N = 708, 11.33%)
- Kidney (N = 496, 7.94%)
- Other (N = 133, 2.12%)

Although it has been estimated that there were 198100 new cases of Prostate Cancer diagnosed in the US in 2001 and only 7200 cases of Testis Cancer [34], the relative frequency of Testis Cancer queries was quite high. One possible reason might be that males diagnosed with Testis Cancer are generally much younger than those diagnosed with Prostate Cancer, and those younger individuals might be more-frequent information seekers on the Internet. It may also reflect the fact that the 2001 Tour de France bicycle race won by Lance Armstrong, a Testis Cancer survivor, was held during July, coinciding with the study period for this project.

As with most sites, the most-common Prostate Cancer questions were General Information (N = 1715, 54.6%). For Prostate Cancer, there were more questions about Treatment (N = 460, 14.65%) than Symptoms (N = 364, 11.59%). This may reflect major medical controversies about treatment options and the typically asymptomatic presentation of the disease.

For the Genitourinary category as a whole, there were more questions about Symptoms (N = 854, 13.66%) than Treatment (N = 604, 9.66%).

Expected misspellings of prostate (prostrate) were noted.

### 10.0 Gynecological Cancers

There were 5344 queries overall. The breakdown of subcategories in decreasing frequency was:

- General Information (N = 3409, 63.79%)
- Symptoms (N = 939, 17.57%)
- Diagnosis and Testing (N = 452, 8.46%)
- Treatment (N = 247, 4.62%)
- Definition (N = 158, 2.96%)
- Cause/Risk (N = 83, 1.55%)
- Statistics (N = 42, 0.79%)
- Prevention (N = 14, 0.26%)

In decreasing order of frequency, the cancer types queried in all 8 Gynecological subcategories included the following:

- Ovarian (N = 2031, 38.00%)
- Cervical (N = 1924, 36.00%)
- Uterine (N = 606, 11.34%)
- Endometrial (N = 225, 4.21%)
- Vulvar (N = 166, 3.11%)
- Vaginal (N = 219, 4.09%)
- Other or not specified (N = 173, 3.24%)

There were nearly as many questions about Cervical Cancer as Ovarian Cancer despite the fact that in the United States in 2001 the estimated incidence of new Ovarian Cancers was about twice that of invasive Cervical Cancer [34].

There were questions about Endometrial cancer as well as Uterine cancer. These data suggest that Web site information needs to be provided using both labels.

### 11.0 Head and Neck

There were 2522 queries overall. Most queries asked for General Information (N = 1485, 58.88%). The vocabulary used to ask about specific cancer types within General Information was:

- Throat
- Mouth
- Oral
- Tongue
- Head
- Neck

The vocabulary confirms the need to offer health information with words that are not technical like larynx, glottis, pharynx, or nasopharynx. There were 59 questions asking about Definitions of Head and Neck cancer. Specifics about cancer anatomy of this cancer type may be less familiar to the general public than other sites.

There were 422 queries asking for Pictures of Head and Neck Cancer. There were only 47 questions (1.86%) asking about Cause/Risk/Link issues, despite the fact that there is a great deal known about the Causes and Prevention of Head and Neck Cancer. There were 418 questions (16.57%) about Symptoms and but only 52 (2.06%) about Treatment.

### 12.0 Hematologic and Blood Cancers

Among 5448 queries in this category, the 5 most common of the 12 subcategories were: General Information (N = 3781, 69.40%), Definition (N = 701, 12.96%), Symptoms (N = 539, 9.89%), Treatments (N = 175, 3.21%), and Organizations (N = 102, 187%). Within General Information users asked about Leukemia (N = 2895, 76.57%), Myeloma (N = 592, 15.66%), Bone Marrow (N = 148, 3.91%), and Blood Cancers (N = 146, 3.86%). Various misspellings of Leukemia were noted and nontechnical terms such as Blood Cancer and Bone Marrow Cancer were frequent.

### 13.0 Lung Cancer

Lung Cancer (N = 4630) accounted for 8% of organ-type specific queries within the highest-level Cancer category. This is a disproportionately-low percentage given the relative incidence of Lung Cancer in the United States in 2001 [32]. There were more queries about Gynecological and

Hematologic/Blood cancers, even though the US incidence for these is far lower.

Among Lung Cancer queries, the queries were classified as follows:

- General Information (N = 3223, 69.61%)
- Symptoms (N = 530, 11.45%)
- Cause/Risk/Link (N = 305, 6.59%)
- Treatment (N = 219, 4.73%)
- Definition (N = 150, 3.24%)
- Statistics (N = 113, 2.44%)
- Diagnosis and Testing (N = 90, 1.94%)

In the Cause/Risk/Link category of Lung Cancer, there were only N = 180 queries (59.02%) that asked generally about Causes of Lung Cancer and N = 102 queries (33.44%) that asked specifically about Smoking. There were N = 23 queries (7.54%) asking if Marijuana caused Lung Cancer.

Only N = 255 (7.91%) queries within General Information asked about Lung Cancer by (histologic cell) Type, despite the fact that this is a major determinant of triage for treatment.

For Lung Cancer > Treatment, there were 219 queries (4.73%). Most Treatment queries were Unspecified (N = 118, 53.88%), eg, "What are treatments for lung cancer?" There were 26 Treatment questions about Cure (11.87%). There were few specific questions about Medications (chemotherapy) (N = 21, 9.59%), Radiation (N = 19, 8.68%), or Surgery (N = 10, 4.57%). Although all numbers were small, there were more questions about Alternative Treatment (N = 13, 5.94%) than Surgery (N = 10, 4.57%). There were only 4 Treatment questions (1.83%) about palliative care, despite the grave prognosis for most Lung Cancers. Clearly the questions about Lung Cancer, the most-common lethal cancer, were far less sophisticated than the questions about either Breast Cancer or Prostate Cancer.

### 14.0 Lymphomas

Among the 3333 queries about Lymphoma (including both Hodgkin's Disease and Non-Hodgkin's Lymphoma), General Information (N = 2391, 71.74%) questions were the most common. Unlike many cancer types, there was frequent mention of histologic types, as is appropriate, given the wide variety of clinically-different prognoses and treatments in this subcategory. There were many different spellings of Hodgkin's Disease.

### 15.0 Miscellaneous Cancers

There were 1633 queries assigned to this Cancer subcategory. The Miscellaneous Cancers were:

- Endocrine (N = 901, 55.17%)
- Neoplasm (N = 272, 16.66%)
- Kaposis (N = 262, 16.04%)
- Ocular (N = 179, 10.96%)
- Germ Cell (N = 19, 1.16%)

Several of the Ocular queries, eg, Ocular Melanoma and Retinoblastoma, could have been considered for other subcategories, such as Skin and Pediatric respectively. Germ cell tumors could also have been placed in either Genitourinary or Gynecological subcategories. These ambiguities illustrate the difficulty in categorizing precise user information needs despite the use of natural language processing.

### 16.0 Pediatric

There were only 603 Pediatric queries, and most asked about a specific cancer type (N= 403, 66.83%). There were relatively few General Information queries (N = 81, 13.43%) eg, "where can I find information on children's cancers?" Since patients with Pediatric cancers in the US are usually managed generally by pediatric oncology specialists at major regional medical centers, those seeking Pediatric cancer information are probably directed to specialized Web sites rather than general sites like Ask.com.

Of 403 queries for cancer types, the most common were Hematologic/Blood (N = 137, 34%), Neuroblastoma (N = 133, 33%), and Rhabdomyosarcoma (N = 68, 16.87%). There were only 4 questions referring to pediatric Brain and Neurological cancers. Since this is such a common Pediatric tumor type, it is possible that some Pediatric neurological tumor questions were assigned to the Brain and Neurologic Cancer category even though the questions were really meant to target a Pediatric issue.

### 17.0 Skin Cancers

Among 6709 queries in this Cancer subcategory, 3596 (53.60%) asked for General Information. Like Lymphoma, there was frequent mention of specific Skin Cancer types (N = 2157, 32.15%), probably because of the significantly-different clinical prognoses and treatments.

Only 169 queries (2.52%) asked about Cause/Risk/Link, and 60 queries (0.89%) asked about Prevention despite the fact that so much is known about these topics and Skin Cancer.

Among Skin Cancers queried by histologic cancer type (N = 2157, 32.15%), Melanoma was the most common (N = 1707, 79.14%), even though it is far-less common than Basal Cell Skin Cancers (N = 322, 14.93%) [10]. Frequent mention of Melanoma probably reflects its more-serious prognosis and more-complicated clinical triage.

### 18.0 Soft Tissue Cancers

There were 3954 queries in this Cancer subcategory. Although most appropriately refer to sarcomas of various types, there was a minority of misplaced queries. Some queries appear to reference conditions that are probably benign (Ganglion, Fibroid, Dysplasia, and Lipoma) and others should have been placed in different Cancer subcategories eg, Brain and Neurological (Oligodendroglioma and Glioma) These will be corrected on later analyses.

### 19.0 Treatment

In the 3832 highest-level category queries about Treatment, most questions were about a specific Treatment Type (N = 3223. 84.11%), even though no specific cancer was mentioned. Within Treatment > Treatment Type there were many general queries about Chemotherapy (N = 2275, 70.59%). There were questions about general Radiation Therapy (N = 534, 16.57%), and few about specialized Radiation Therapy treatments like Gamma Knife, Laser, and Protons. There were more general questions about Alternative Therapies (N = 239, 7.42%) than Surgery (N = 127, 3.94%) Many Alternative Therapy questions also appear in specific organ-type subcategories, particularly Breast.

### Query Frequency Relative to US Incidence of Cancer Types

Table 4 compares the incidence of selected cancers in the United States (US) in the year 2001 with the frequency of selected site-specific cancer queries in this report. It has been estimated that there were 1268000 new cancer cases in the US in 2001 [34]. The sites in Table 4 were selected specifically because they were easiest to compare directly.

The relative percentage of specific organ-type queries exceeds the percentage of annual incidence only for rarer cancers. The difficulty of finding useful information on prominent cancer portals or with standard search engines may be one explanation, although there are others. The comparison is not meant to be definitive as there are clearly issues with validity of this comparison:

- Cancer prevalencemight be a better benchmark than incidence
- US incidence data exclude cases of in situ breast and cervix cancers as well as the very-common basal cell and squamous cell skin cancers
- Queries could have come from anywhere in the world, not just the United States
- Query total may include those who accessed the site more than once
- Queries could have come from individuals who are not newly-diagnosed patients

**Table 4.** Comparing relative annual US incidence of selected cancers and query frequency

| Cancer Site | Estimated Number of New US Cancers Diagnosed in 2001 * | % of Estimated New US Cancers in 2001 * † | Number of Cancer Site-Specific Queries in This Report | % Queries in Cancer Category † ‡ |
|---|---|---|---|---|
| Digestive (D/G/B) | 235700 | 18.6 | 8959 | 15.0 |
| Prostate | 198000 | 15.6 | 3141 | 5.3 |
| Breast | 193700 | 15.3 | 6953 | 11.7 |
| Lung | 169000 | 13.3 | 4630 | 7.8 |
| Lymphoma | 63600 | 5.0 | 3333 | 5.6 |
| Bladder | 54300 | 4.3 | 708 | 1.2 |
| Uterus/Endometrial | 38300 | 3.0 | 931 | 1.6 |
| Head and Neck | 30100 | 2.3 | 2522 | 4.2 |
| Ovary | 23400 | 1.9 | 2031 | 3.4 |
| Brain and Neurological | 17200 | 1.4 | 1852 | 3.1 |
| Cervix | 12900 | 1.0 | 1924 | 3.2 |
| Soft Tissue | 8 700 | 0.69 | 3954 | 6.6 |
| Testis | 7200 | 0.57 | 1772 | 3.0 |

[*] Data from 2001 Estimated Annual US Cancer Incidence Figures (N = 1268000) [10].

[†] Percentages in columns 3 and 5 do not add up to 100% because only selected cancers were included in this chart.

[‡] Only selected Cancers were included in this chart. Denominator (N = 59619) was the total number of queries about specific subsites in the Cancer category.

### Other Observations

The query analysis reveals that online users generally seek information about Symptoms and Treatment for specific cancers, rather than about cancers generally. In addition, Symptom queries showed a frequency between 2 and 5 times that of Treatment queries, for most cancers.

For this study we did not specifically target queries about Adult Immune Deficiency Syndrome (AIDS), even though AIDS can often be associated with Cancer. There were 262 questions about Kaposi's Sarcoma in the Miscellaneous Cancers category.

## Discussion

General Information was the largest category for almost all cancers, probably reflecting the nature of the Ask.com consumer search engine. It is a consumer-oriented Web-wide search engine where users tend to seek general information that can help them learn either how or where they should further pursue their inquiries. It is likely the users are just starting their Web searches on Ask.com and they are not yet interested in or they do not yet know enough information to ask more-sophisticated questions. This behavior may not reflect that of users who go directly to a known cancer-information portal with a predetermined need for detailed information.

We attempted to capture and analyze all cancer-related queries, including those with correct and incorrect spellings. Misspellings were noted relatively frequently, but we have no data on the number of misspellings, as we did not target this in advance as an endpoint, and we did not have direct access to the raw data logs. Appendix 1 shows verbatim queries with examples of the misspellings. Automating help for users who enter misspelled words is a major issue for search engines in order to optimize query results. Other researchers have noted the search difficulties related to spelling of cancer search terms correctly [35].

Ask.com users entered both keyword searches and sentence-style queries, despite the fact that this is a natural-language-processing search engine. We recognize that even if users typed in a long query it was still sometimes difficult to discern absolutely what specific information the user needed, particularly since we did not have access to the links users picked.

The vocabulary employed by users of Ask.com ranged from unsophisticated to very sophisticated. This suggests that allowing users to employ less-technical language on cancer Web sites would significantly help them find the information they seek.

The queries captured for this study undoubtedly reflect the news and research studies in the public arena during the time period from June to August 2001. A different time period would certainly reflect a different distribution. Examples of the kinds of events that could affect the results include the diagnosis or death of a celebrity with cancer, the publication of a major trial about bone marrow transplantation for breast cancer, or the Food and Drug Administration approval of an important new drug.

The presence of a search engine with natural language processing on a Web site, while potentially valuable to users, does not obviate the need for good user-centered Web site design and information architecture [36]. It has been shown that searching via search engine can be minimized and user satisfaction maximized if information architecture and link titles follow appropriate guidelines [37]. Nevertheless, for less-sophisticated users, a natural-language-processing search engine can be helpful in finding the information users seek and provide enhanced success in searching.

An October 30, 2003 search of the PubMed Web site [38] of the National Library of Medicine [39] yielded 458 search results from a query for "Natural Language Processing." Most citations were from publications within the last 3 years, attesting to the currency of natural language processing as an important research topic cutting across a wide variety of research disciplines. Potential data-mining applications of this tool in medicine extend far beyond the use described in this paper.

Eysenbach and Kohler have recently developed a novel methodology, similar to the method used in this study, to estimate the actual volume and prevalence of health-related searches on the Web in relation to the total number of searches conducted daily on the Internet [40]. They collected queries from 2 search engines, Metacrawler (a search engine of search engines) [41] and Ask.com [29] (the same natural-language-processing search engine used for this report). These 2 search engines were selected because they allowed "peeking" at actual user search-query topics. They concluded that 4.5% of all searches on the Web might be health related. The queries were collected from Metacrawler between February 2001 and April 2002, and from Ask.com between February 2001 and April 2001. The first date range overlapped our study dates and the second occurred just before data collection for our study.

In summary, natural-language-processing tools such as the one used for this study are able to filter and subset raw query data into useful analysis categories. Retrieval and analysis of these data can be used to better understand the actual content users want and the level of understanding and sophistication they have when they come to the Web site. Using the information on a continuing basis can form the basis for updating content on Web sites based on the most-current user needs. If a natural-language search engine were offered on a health-information portal, for example, it could improve customer access to desired information, particularly for those users with less sophistication about content or language. Additional analyses of query results are planned for the future. Consideration has been given to piloting the use of natural language processing on subsites of our Web portal.

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## Conflicts of Interest

None declared.

## Data Supplement Appendix: Data Categorization, Counts, and Charts

Click here for complete Data Supplement Appendix: [ZIP File, 2.9M - jmir_v5i4e31_app1.zip ]

## Overview

Appendix 1 contains the counts and exact wording for all of the categorized questions from the sample of 7,500 user questions. Each category (such as *Breast or Head & Neck*) will have the highest level of breakdown on the first page, and subsequent breakdowns (if possible) on that page and following pages.

## Rounding in Pie Charts

When looking at certain pie charts in Appendix 1 there will be categories that are shown to be 0%. This is due to rounding of numbers in Microsoft Excel. The actual percentage can be seen in the tabular format.

## Additional Information in Pie Charts

The charts embedded within the Appendix can be double clicked to reveal additional information.

## Tables

Most categories are broken out into tables with 4 columns. An excerpted example is shown below before the actual data tables are displayed. It shows the breakdown of Brain and Neurological Cancer > General Information > Cancer Type. The columns contain the following information:

- The first column starts with the category name in a yellow cell. In the example shown this is Cancer Type. Below Cancer Type are the types of cancers found within that category. For other categories, these would be the representative terms for that category, ie, for a category such as Treatment there might be listings for Alternative, Chemotherapy, Surgery, and Radiation.
- The second column of the illustrative table contains the raw count of user queries for that field. As shown in the example, Astrocytoma was queried 144 times, which is 33.72% of all queries that are found in the subcategory of Cancer Type.
- The third column shows the percentages for that subcategory. These are category specific, meaning that they are percentages of only those terms within that category or subcategory. Therefore Benign cancers represent 2.81% of all Cancer Type queries and are not 2.81% of all Brain & Neurological Cancer queries. While it was not the intention to include benign queries in this analysis, a small number were captured and analyzed, and therefore appear in the tables.
- The fourth column header notes where the subcategory is in relation to the main category. In this case Cancer Type was created within the General Information category of the cancer site Brain & Neurological Cancers. The counts are also included, to illustrate that out of the total number of Brain & Neurological Cancers (N = 1852 queries), General Information queries accounted for 1323 queries, which were 72% of all Brain and Neurological Cancer queries. Within the subcategory of General Information there is another subcategory of Cancer Type which accounts for 427 queries or 32.28% of all General Information queries. Included in the fourth column underneath this relationship map are examples of actual user queries for the terms on the left. Neither spelling, nor punctuation nor capitalization has been corrected. These and all queries are taken directly from the logs, with the goal of illuminating the types of queries that the users are asking. Sometimes users type full, even excessively-long queries, and other times, they choose to use keywords.

It might not be possible to strictly compare categories for one Cancer Type to another because each analysis is driven by the user queries themselves. If 50% of all users asking about Breast Cancer had asked about Treatment, but no one querying Lung Cancer asked about treatment, there would be no Treatment subcategory under Lung Cancer.

Excerpted example illustrative of table contents (see explanation above, in Tables)

**Table A1.** General Information

| |
|---|
| Brain & Neurological 1852 - General Information 1323 72% Cancer Type 427 32.28% |
| how can I get information on glioblastoma |
| Astrocytoma Brain Tumor Research Online |
| find information on medulloblastoma |
| BENIGN BRAIN TUMORS |

## Bone Cancer

**Figure A1.** Bone Cancer

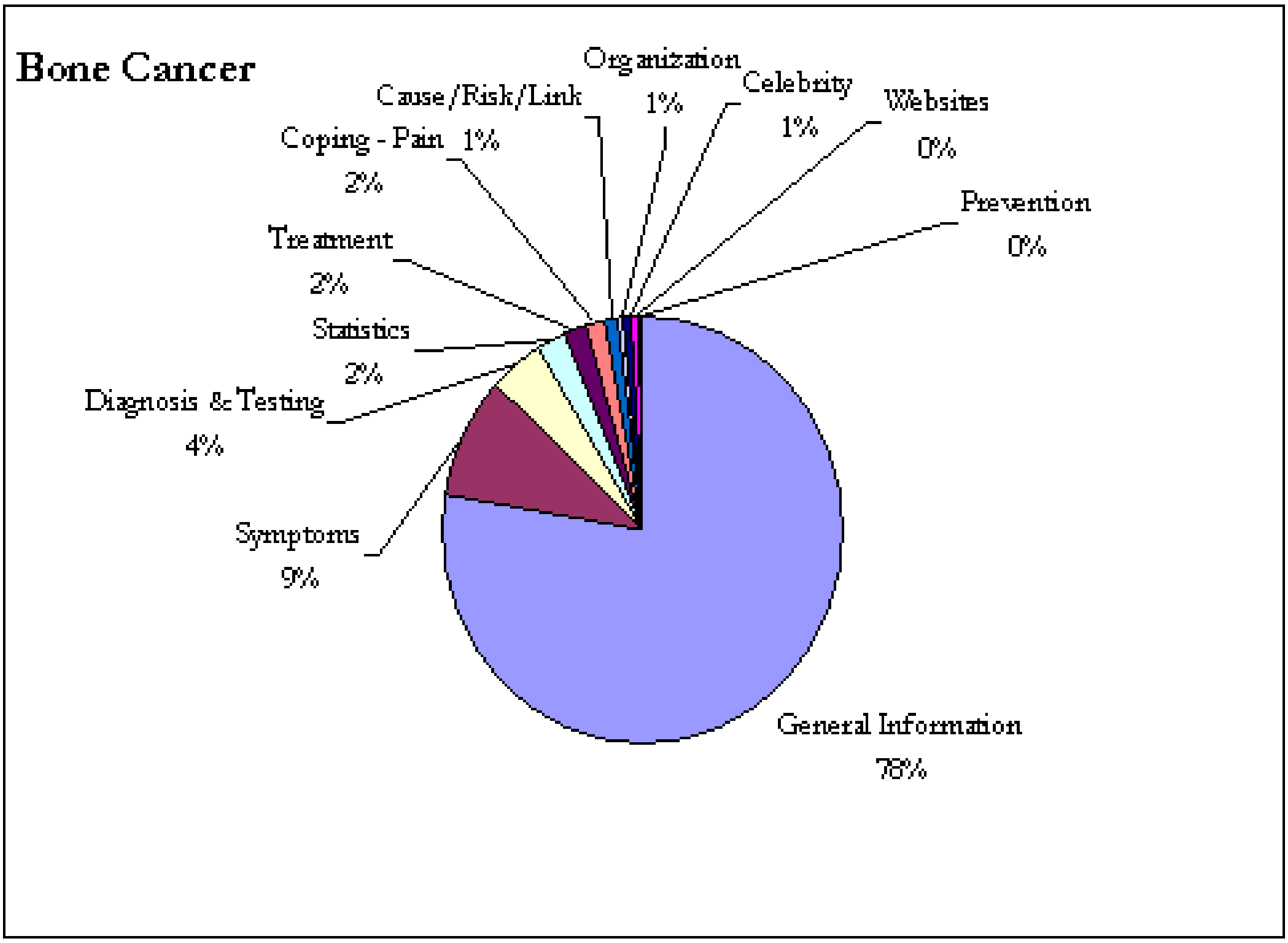

**Table A2.** Bone Cancer

| | Bone Cancer Total Count 1429 |
|---|---|
| General Information | Where is information on bone cancer? |
| | What are the symptoms of bone cancer in teenagers? |
| Diagnosis &Testing | What is a bone marrow biopsy? |
| | What is the life expectancy of someone diagnosed with bone cancer? |
| | where find bone cancer treatments? |
| | how to deal with bone cancer pain? |
| | will agent orange cause bone cancer? |
| | bone cancer and the american cancer society |
| | which u.s. president had cancer in his left jaw? |
| | what are good web sites to look up bone cancer? |
| | prevention of bone cancer? |

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## Abbreviations

**AIDS:** Adult Immune Deficiency Syndrome
**ACS:** American Cancer Society
**D/G/B:** Digestive, Gastrointestinal, and Bowel
**NCI:** National Cancer Institute
**US:** United States

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Original Paper

# Conceptual Framework for a New Tool for Evaluating the Quality of Diabetes Consumer-Information Web Sites

Joshua J Seidman[1], PhD; Donald Steinwachs[2], PhD; Haya R Rubin[3], MD, PhD

[1]Center for Information Therapy, Healthwise, Inc, Washington DC, USA

[2]Department of Health Policy and Management, Johns Hopkins University, Bloomberg School of Public Health, Baltimore MD, USA

[3]Departments of Medicine, Epidemiology, and Healthy Policy and Management, Johns Hopkins School of Medicine, Bloomberg School of Public Health, Baltimore MD, USA

**Corresponding Author:**
Joshua J Seidman, PhDExecutive Director
Center for Information Therapy
Healthwise, Inc
600 New Hampshire Avenue NW
Washington DC 20037
USA
Phone: +1 202 945 6810
Fax: +1 202 266 6068
Email: jseidman@healthwise.org

## Abstract

**Background:** Most existing tools for measuring the quality of Internet health information focus almost exclusively on structural criteria or other proxies for quality of information, rather than evaluating information accuracy and comprehensiveness.

**Objective:** This research sought to build a conceptual framework that could lay the groundwork for a robust performance-measurement system for evaluating the quality of Internet health information.

**Methods:** Application of the quality-of-care measurement paradigm to developing a conceptual framework for defining and evaluating the quality of diabetes consumer-information Web sites.

**Results:** Performance measures related to accuracy and comprehensiveness of information can be added to structural criteria to provide a more-robust approach to Web site evaluation.

**Conclusions:** The development and implementation of a reliable and valid method for evaluating the quality of Internet health sites could provide lay people with a tool to identify useful content more easily and distinguish between beneficial and misleading information.

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**KEYWORDS**

Internet/standards; information management/standards; medical informatics/standards; guidelines; quality of health care; diabetes

## Introduction

It has become increasingly common for consumers to gather information on their own about medical care for themselves and their families. In the last few years, the increasing involvement of consumers in medical care decisions has dovetailed with the explosion of the World Wide Web as an accessible information source. These 2 forces theoretically have the power to reshape the organization and delivery of modern medical care by reducing the enormous asymmetry that exists between patients and their doctors. That metamorphosis cannot transpire, however, unless lay people can access reliable, accurate information in a digestible form. Mark Twain said "a lie can travel halfway around the world while the truth is putting on its shoes" (in an era when the fastest means of long-distance communication was the Pony Express). With the Internet, misinformation can travel around the world multiple times and potentially adversely affect many people's lives.

Despite the proliferation of health care Web sites little oversight of health care content exists, and no widely-accepted method for evaluating the quality of health and medical information on the Internet has been integrated into the health care system. Although lay people have successfully found valuable information about their diseases on the Web, their ability to do so depends largely upon the particular condition, the sophistication of the consumers themselves, their access to resources, the amount of time they have available to gather information, and luck. In addition to the frustration of lay people unable to find understandable information as they struggle to handle a potentially-devastating condition, this process can produce other negative consequences. Without an adequate medical background, consumers may seize on misleading, incorrect, or oversimplified information that can be potentially harmful to them and enervating for their clinicians, because the latter often have to disabuse their patients of misinformation. Little research exists to document whether the Internet has directly caused harm—thus far, only a few anecdotal reports have been cited in the literature [1]—but Eysenbach and Kohler have initiated an online-database effort to collect such information [2].

The development and implementation of a valid method for evaluating the quality of Internet health sites could provide lay people with a tool to locate useful content more easily and have confidence the information is accurate and complete. Access to accurate and digestible information has the potential both to empower lay people and to raise the level of dialogue between them and their clinicians, thus enriching the patient-clinician relationship and ultimately improving the quality and efficiency of health care delivery.

### Impact of the Internet on the Health Care Delivery System

Never has the world of science and medicine been so immediately accessible to lay people. The Institute of Medicine report, Crossing the Quality Chasm, notes that the Web can bridge the chasm between doctor and patient and elevate their level of dialogue, allowing them to discuss diagnostic and treatment choices in a more sophisticated and timely manner [3]. Richer clinician-patient conversations preceded and followed by electronic educational tools offer an opportunity for sounder health care decision making, better information management, and more thorough and comprehensible disease management.

That potential, however, has by no means been realized, perhaps due in part to the inadequacies of the current state of available information. Although the health information available on the Internet may not be any different than the information that can be found through more traditional means, the sheer volume of it and the speed with which lay people can access it has implications for both its potential value and drawbacks [4]. As with other nascent technologies, little empirical research exists on the quality of information offered on the Web, but the early evidence suggests current health information is, to varying degrees, incomplete, inaccurate, oversimplified, and/or misleading [5- 11].

## Methods

### Process for Reviewing Existing Health-Information Web Site Evaluation Models

This literature review evaluates research and work presented not only in the traditional peer-reviewed literature, but also on the Internet. Several factors contribute to the reality that a majority of the work done in the area of the quality of health information on the Internet can be found on the Web and not in the peer-reviewed literature. First, given the embryonic stage of the subject, the speed to "publication" of the Web means that considerably less time has elapsed relative to the slower process of traditional peer-reviewed literature. Second, some would argue that the prevalence of commentary and review of the Web is much greater on the Internet than in paper, peer-reviewed literature. Third, evaluation of health Web sites crosses multiple academic disciplines and lay consumer interests, rendering it more appropriate in some senses for alternative distribution channels.

### Gathering Evaluation Criteria From Existing Models

Some studies to evaluate existing Web sites have already been conducted, although the body of evidence changes so rapidly that no review can be completely thorough or up to date (including this one). One of the more-recent systematic reviews was conducted by Eysenbach et al in 2002 [12], which assessed 79 distinct studies that met their inclusion criteria. As described in Table 1, included studies most frequently used technical criteria and accuracy, whereas completeness, design, and readability were employed to a considerably-lesser extent. There was enormous variation not only in the approaches used to assess criteria but also in the quality of the methodology in doing so.

We reviewed several other published tools and online instruments to identify both additional criteria and more-refined definitions [13- 21], with most criteria fitting into the categories described above. In many cases, authors listed criteria with minimal or no technical definition, leaving specification to each individual user of the system, vastly limiting capacity for standardized comparisons of Web sites by multiple users.

The desire to create empirical methods of Web site evaluation has led some researchers to experiment with the development of automated tools for health Web site evaluation. Price and Hersh [22] developed a computer program with the goal of assessing a site's likely relevance, likely credibility, likely bias, content, currency, and value of links. The rudimentary algorithms developed for this computer program were marginally successful in identifying clearly "undesirable" Web pages, but certainly could not provide a more-refined evaluation. Shon and Musen [23] found that even creating a rudimentary automated method for Web site evaluation was virtually impossible because many basic publishing elements were described on Web sites less than half the time: authorship (20%), attribution/references (32%), disclosure (41%), and currency (35%).

Some research has focused on the development of self-assessment methods for Web site evaluation, although few have attempted to evaluate these models. Jones [16] presented findings in 1999 on such a method, but the criteria used were highly subjective and therefore do not necessarily provide a useful tool for other users.

**Table 1.** Studies that met inclusion criteria of Eysenbach et al's systematic review [12]

| Criteria Group | What It Includes | Criteria | |
|---|---|---|---|
| | | Number | % |
| Technical criteria | Disclosures of authorship, ownership, sponsorship, advertising, dates, credentials, affiliations, or other.<br>Provision of links, references, feedback mechanisms, contact information, or disclaimers.<br>Explanation of sources, purpose, copyright, editorial review process, hierarchy of evidence, or balanced evidence.<br>Ease of navigation and searching.<br>Appropriate writing style (subjective). | 53 | 67 |
| Accuracy | Developed criteria prior to assessment.<br>Evaluated claims without prior development of tool. | 47 | 59 |
| Completeness | Percentage of a priori-defined elements covered.<br>Balance of information presented. | 19 | 24 |
| Design (aesthetics) | Visual aspect of site.<br>Layout.<br>Use of visual analog scale. | 15 | 19 |
| Readability | Use of Flesch-Kincaid or other readability formulas.<br>Little attempt to assess comprehension. | 11 | 14 |

One of the most-recent attempts to evaluate the quality of health Internet information comes from researchers sponsored by the European Union. The initial progress report issued by Eysenbach et al [24] in February 2001 indicates that they have chosen to define quality from a user perspective. Eysenbach et al explain, "We define 'quality' of a health Website (health information or e-health service) as the totality of properties (features and characteristics) that bear on its ability to satisfy stated or implied needs of the user." Eysenbach et al specifically reject the notion that some objective gold standard should be used to evaluate quality of health information. Rather, they argue, "Quality is not 'degree of excellence' in relation to some abstract concept, but is seen in relation to (and must be measured against) the needs and preferences of the users of the product or service." More recently, Eysenbach and Kohler conducted the first laboratory usability study and focus groups to describe consumer techniques for retrieval and assessment of Internet health information [25]. They found that consumers generally reported they could find the information they need despite suboptimal searching techniques and questionable reliance on subjective markers of health-information quality.

# Results

## Building a Conceptual Framework

Multiple approaches to understanding the impact of the Internet on health and health care could be employed to tackle this emerging field of research—perhaps one day to be dubbed *cyberology* or *eHealth services research*. Measuring the quality of health care offers a useful framework for conceptualizing the measurement of the quality of health information. After all, health care is, in part, an information business. With the exception of surgery and other invasive procedures, much of what happens in health care involves the exchange of information, although there are other aspects of communication that shape the patient-provider interaction [26- 27]. In fact, in many cases, the line between health care and health information remains blurred. To some extent, this has always been true, but there are reasons to believe that information will have increasing value in 21st-century delivery systems. The rapid adoption of Internet technology around the world has the potential to expand the capacity of health professionals to interact with their patients and provide patient information and monitoring across the Internet [3]. The Internet, therefore, offers opportunities but with caveats; the opportunity derives from the growth of a tool that allows people to communicate in ways that they always wanted, but that depends on appropriate information flowing to the parties in need of it.

This evolving notion of health-information quality adapted from the quality-of-care paradigm therefore provides the basis of a solid framework for evaluating the quality of health-information Web sites. Although high-quality health information generally is a prerequisite for quality health services, it does not guarantee effective care; it is a necessary but not sufficient condition. It is important to distinguish between the quality of the information itself and the quality of the use of that information. The latter basically reflects the quality of care. As a corollary, while image quality associated with MRI machines is necessary to ensure high-quality radiology care when that test is conducted, less-than-optimal use of that technology can result in poor quality even if the image quality is excellent. The difference, of course, is that consumers cannot access MRIs simply by sitting down at their home computers, but the Internet has helped to provide patients with an enormous amount of health information.

## The Quality-of-Care Measurement Framework

The field of quality-of-care measurement provides a solid foundation for understanding how to measure the quality of health information. Perhaps the most commonly-cited definition of quality of care is the one developed by the Institute of Medicine, which states that quality in health care is "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge" [28].

Donabedian [29] suggested that quality-of-care measures can be separated into 3 categories: structural measures, process measures, and outcome measures.

Structural measures address the underlying systems and infrastructure: are systems in place and are the right types of people assembled in the right way to allow for the provision of quality care? Accrediting bodies—such as the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) [30], the National Committee for Quality Assurance (NCQA) [31], and the Utilization Review Accreditation Commission (URAC) [32]—have historically employed accreditation standards that address many structural factors, such as appropriate credentialing of physicians and evidence of effective quality-improvement projects. An example for diabetes might be determining whether a doctor has additional training or board certification in endocrinology or diabetes. Evidence has often been lacking that structural criteria actually relate to delivering better health care process, as defined below.

Process measures—such as NCQA's HEDIS (Health Plan Employer Data and Information Set) [33] measure of whether patients received an annual referral to an ophthalmologist for retinal screening—assess the extent to which health care providers have done the right things, that is, provided those specific treatments and behavior that have been proven to improve desired patient-health outcomes for similar patients. The value of a process measure depends on the strength of the evidence that links it with ultimate outcomes. Outcome measures, in contrast, address the end results of medical care (eg, for diabetic patients, symptoms, level of blood sugar or hemoglobin A1C achieved, vision, quality of life, or mortality) [34].

The advantages and limitations of process and outcome measures have been discussed elsewhere [35]. Briefly, structural and process measures are only as good as the evidence that relates them to health-outcome benefits for similar patients. However, evidence has not been gathered for all-important clinical situations, such as those with rare diseases or combinations of common conditions that have not been studied together.

On the other hand, outcomes are not feasible or valid in all situations. Many factors outside of health care providers' control affect patients' outcomes. If outcomes are to serve as measures of health care quality, they should be compared to outcomes for similar patients. Yet such risk adjustment or stratification techniques do not exist for many outcome measures or omit important factors (see HEDIS [33] for examples). For example, hemoglobin A1C levels in diabetes will vary depending on how well patients adhere to health advice and instructions. The entity being measured may have control over only a limited number of patient care factors or processes (eg, nonadherence, difficulty in affording medications, and other medical conditions); thus, outcome may be influenced by factors beyond the provider's or health plan's control. Transforming a limited evidence base into a body of health information for consumers involves challenges that are similar to those for transforming that modest evidence base into performance measures. This is why Donabedian expected that performance measures typically would be developed from the starting point of an evidence base, but generally would have to be supplemented by expert opinion [29].

A combination of structure, process, and outcome approaches may produce the best assessment of quality of care. For example, NCQA released a performance measure [36] in 1999 to assess cholesterol management after acute cardiovascular events through a process measure (whether a lipid profile was performed within one year after a heart attack or revascularization) linked with an intermediate outcome measure (whether the patient's low-density lipoprotein [LDL] cholesterol level was controlled to less than 130 mg/dL between 2 and 12 months following the event).

Performance indicators—be they process or outcome measures—provide quantitative feedback as to whether some quality-improvement intervention actually produced a desired change. Whereas a structural measure might ask whether the health plan targeted high-risk individuals and encouraged them to get their cholesterol measured, a performance measure actually gauges their performance in getting those people tested—even before the further step of specifically reducing their cholesterol levels.

One final way that Donabedian suggests for thinking about how measures serve different purposes is to contrast technology assessment with performance assessment. Whereas the former "are activities meant to determine the right things to do (or the right ways to behave)," performance measures are "meant to determine if the things known (or presumed) to be the right things to do (or the right ways to behave) have in fact occurred" [37].

This dichotomy between structural and process measures has particular relevance to the current state of the evaluation of health information on the Internet. Most of these efforts have exclusively included criteria focusing on the process by which information is developed; did the authors follow a process thought to increase the likelihood of producing accurate information (eg, peer review)? In other words, did the developers of information "behave" the right way? In contrast, little work has been done to evaluate the content of Web sites; for example, did the Web site actually produce information that was accurate and comprehensive? This shift offers more than a shift from structural to process criteria because it also has the potential to complement static, qualitative assessment with dynamic, quantitative measurement, much the same way NCQA has combined on-site accreditation (done once every 3 years) with annual HEDIS reporting of performance measures. Relative to Donabedian's quality-of-care measurement dichotomy, the performance measures would allow us to assess whether the right information has in fact been given to consumers.

## Development of a Systematic Approach to Web Site Evaluation

How can we put into operation this goal of applying performance measurement to assessment of the quality of information? The first step is to realize that, although a variety of Web site evaluation tools have been developed, virtually none of them derive from a scientific development process. The creation of qualitative evaluation systems, however, can be a scientific process if it relies on objective, systematic criteria that are applied in a consistent and reliable way.

A data abstraction tool that employs a defined set of reviewer criteria lays the foundation for an objective evaluation system to assess the credibility of health information on Web sites. The techniques can be deemed reliable if they can be consistently repeated to produce the same results. The techniques can be judged valid if they measure what they purport to measure.

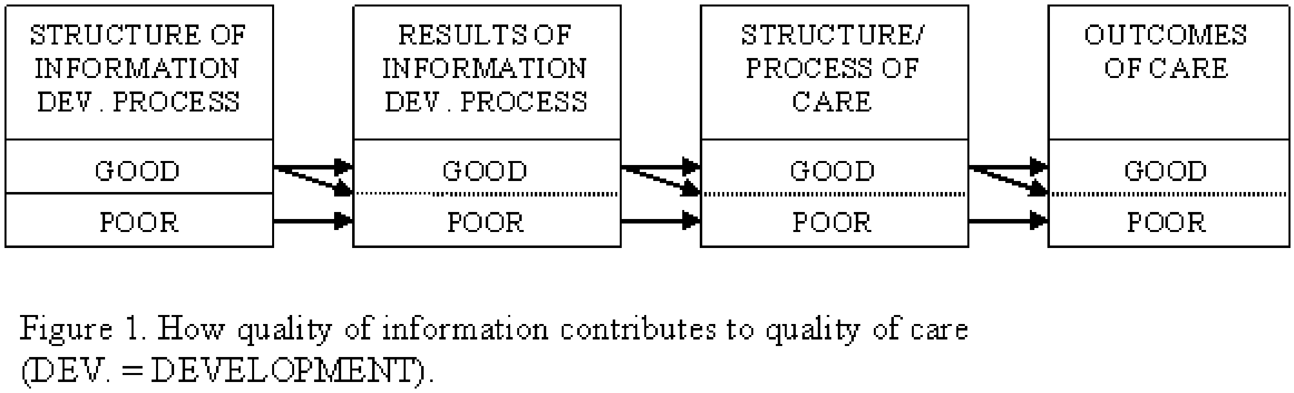
## Translating the Quality-of-Care Conceptual Framework to Internet Health Information

Although quality-of-care measurement provides a useful framework for thinking about measuring the quality of health information, not all elements of that paradigm can be easily translated. Most importantly, as far as we are aware certain types of epidemiological and health-services research have never been conducted to answer specific questions regarding the impact of Internet health information on health outcomes. Ultimately, as with most other health interventions, one would want to know how specific types of Internet health information affect users in terms of health status, morbidity, and mortality. Although considerable research has been conducted to evaluate the impact of specific patient-education interventions on various outcomes—particularly in the areas of asthma [38- 42], diabetes [43- 44], and recovery from bypass surgery [45]—this research has involved structured and organized interventions. In some cases, these targeted interventions have involved self-care or self-management, but none of these studies specifically involved the Internet. It may be difficult to generalize findings from the existing literature to the less-structured, more-independent nature of Internet-based patient education.

The European Union has sponsored a group of researchers to create an "action plan for safer use of the Internet," [24] and in their first report on evaluating the quality of health information on the Web, Eysenbach et al addressed this issue of the relationship between health information and outcomes. They stated that the "ideal methodology to develop a reliable and valid instrument for evaluating Websites would be to start with some criteria with 'face validity,' applying these criteria to sites and comparing it to the health outcomes of people having used the site/service" [24]. In the same publication Eysenbach et al, however, point out that such an ideal is not currently possible and may never be so. They write, "Such a model does not exist, and the methodological challenges for creating such an instrument are huge (starting with the problem of determining the outcomes of patients)." They conclude: "It is questionable whether a reliable and valid instrument developed along these lines can ever exist."

Despite this lack of available outcome research, Eysenbach et al [24] do not differentiate between what can be understood as 2 distinct notions, "the quality of health information" versus "the quality of health care." In contrast, the conceptual framework presented here specifically employs proxy measures to develop a systematic, measurable, objective method for evaluating Internet health-information quality. This method can still use some of the same principles from Donabedian's [29] structure-process-outcome paradigm. With respect to structural measures, one can assess whether the Web sites explain their methods for generating and updating health content, referencing sources, and instituting a peer-review process. Although health outcomes probably cannot be assessed, one can develop performance measures that address the outcomes of the health-information development process, in terms of the comprehensiveness and accuracy of the information provided compared with a gold standard. High-quality health information often is a prerequisite for high-quality care since information plays a critical role in most health care encounters. As shown in Figure 1, structural and process quality for information can often lead to good health information, which in turn can lead to high-quality health care processes, and ultimately to good health outcomes.

**Figure 1.** How quality of information contributes to quality of care



In Figure 1, good information-development processes are generally a necessary but not sufficient condition for producing information that truly is of high quality. That is, high-quality information processes can lead to either good or poor information, but poor processes will almost invariably lead to poor information quality. Similarly, a process that has performed well in producing high-quality information can lead to good health care processes, but poor information quality will virtually always result in poor care. One usually cannot achieve high-quality processes or outcomes of care without first having established that good results were achieved in the information-development process.

Definitions of quality may also vary depending on the objectives of those developing a particular Web site as well as the intentions of those seeking specific health information. Information may be high quality in terms of its accuracy and comprehensiveness but might not offer any therapeutic value if it does not drive user action or comfort the information seeker. In some instances, a consumer may already have all of the information he or she needs, but may seek a health Web site to assist with behavior change or emotional support. Such dimensions of quality in some ways move further down the chain of events to addressing the ability of a Web site to drive improvement in health outcomes. Future research should address these needs (see section on "Process for Creating a New Web Site Evaluation Model" below)—ideally, a user could go to one place to find both accurate-comprehensive information and support for behavior change goals and emotional needs—but they are somewhat distinct from the issues of whether the information itself is credible.

## Discussion

### The Current State of Web Site Evaluation and Oversight

Some evaluation methods have recently been developed to, theoretically, help consumers understand better what information they can trust. Aside from their providers, most consumers historically have relied principally on their friends and family to help them sort out health information; the Web has the effect of extending their community, thus allowing them to tap into a far-greater breadth of assistance, whether through static information, chat rooms, or online support groups. The evaluation models put forth to help consumers, however, have not been adequately tested, have not been adopted broadly, and do not have an infrastructure behind them that could support widespread implementation. A study in JAMA in 1998 by Jadad et al identified 47 Internet health-information rating tools and found that only 30% (14) offered a description of the criteria used, only 11% (5) provided instructions for their use, and none evaluated the interobserver reliability and construct validity of the measurements [46]. They concluded with a warning: "In summary, a large number of incompletely developed instruments to evaluate health information on the Internet exist. It is unclear, however, whether they should exist in the first place, whether they measure what they claim to measure, or whether they lead to more good than harm."

The authors updated their study 4 years later and found little change, except that many of the tools previously available no longer existed. Only 9 of the 47 rating instruments identified in 1997 continued to function. Of 51 newly-identified instruments, 11 were not functional, 35 were available but provided no information to allow for evaluation, and only 5 provided some information by which they could be evaluated. Furthermore, none of the 98 total instruments had been validated [47].

Petra Wilson suggests that tools designed to evaluate the quality of health information on the Internet can be broken down into 5 classifications: codes of conduct, quality labels, user guides, filters, and third-party certification [48]. These have different implications in terms of potential beneficiaries and the costs incurred by site providers, site users, and tool developers. Perhaps 2 of these efforts have garnered the most attention in the United States thus far: the Health on the Net Foundation has initiated a Code of Conduct, and users self-regulate and display the HONcode [49] (a complete listing of the criteria is in Appendix I of the cited reference); and Health Internet Ethics (Hi-Ethics) [50], whose standards have formed the basis of a new third-party Web site accreditation process overseen by URAC.

Organizations pledging to subscribe to the HONcode principles can post the HONcode icon on their Web pages. Although this effort at self-regulation offers a reasonable place to start, in terms of its ability to protect consumers from inaccurate and misleading information, it suffers from a variety of shortcomings. There are 3 overarching issues. First, the criteria are based on vague definitions; without specifications regarding how to evaluate individual sites, interpretation will vary dramatically. Second, the code relies solely on intent of the organization rather than actual performance; although intentionally-misleading information certainly seems more sinister and offends more from an ethical perspective, the damage done by inaccurate information is unrelated to whether it was offered with malice or by accident. One might expect that, regardless of how many organizations voluntarily adopt the HONcode, most health-information Web sites—if queried—probably would state that they abide by the underlying principles. Third, the policy relies entirely on self-policing; that is, the HONcode does not have any mechanism for auditing Web sites to assess whether they adhere to the code's principles.

The other recent self-regulation effort, Hi-Ethics, has broader goals that include protecting consumers' privacy concerns and addressing a range of other issues. As the organization's name implies, the Hi-Ethics principles focus more on ethical issues than health-information quality, although it developed a quality workgroup for its version 2.0 to allow for a more-intense examination of quality.

The first attempt at third-party Web site oversight was launched by URAC, which currently accredits an array of health plans and other health care organizations. URAC's standards, released in final form in July 2001, are based on the Hi-Ethics principles and are "intended for the accreditation of consumer-oriented Web-based electronic activities of health care organizations" [51]. The first 13 Web sites received URAC accreditation in December 2001. URAC's standards represent an important step forward, but they also have substantial limitations, as they are primarily designed to assess structural issues in Web site design and management and do not assess the specific quality or credibility of the information provided on the Web site.

Specifically, URAC's standards involve the following categories of standards: policies and procedures, quality oversight committee, disclosure, linking, privacy, security, accountability, and health content. However, this last category only addresses the Web site's policies and procedures for developing health content rather than any type of assessment of the content itself. Some of the issues addressed by URAC's standards—specifically, privacy and security—are extremely important but not directly related to the concept of health-information quality.

### Process for Creating a New Web Site Evaluation Model

No previous Web site evaluation models have specifically relied on a quality-of-care conceptual framework, and few have developed comprehensive and objective systems (based on a MEDLINE search on November 17, 2003). Probably the most-objective tool developed thus far was by RAND in an attempt to assess the quality of Web sites that provided information about breast cancer, depression, childhood asthma, and obesity [6], although this study only evaluated 10 sites per condition. However, many criteria offered by other health-services researchers, librarians, and Web commentators have merit. Therefore, the first step in developing a new model is to extract any valid and useful criteria from the review of the existing literature (and the Web itself) that are consistent with the quality-of-care conceptual framework.

The second step is to use the quality-of-care framework to identify critical gaps in existing systems—particularly with respect to objective criteria where current systems are most deficient—and add them to the model. One additional issue that remains to be resolved in the evaluation of health-information Web sites is that health information on any given Web site is not necessarily matched to the individual needs of that particular consumer. Ultimately, the system for Web site evaluation must assess practical aspects of computer access through a set of user-functionality criteria, which need to be assessed with research subjects (consumer users) actually navigating through the sites. One future approach to resolving this issue would be to develop a consumer/user survey that could be a component in the performance measurement portion of the evaluation tool, much the same way that the CAHPS (Consumer Assessment of Health Plans Study) survey has been integrated into HEDIS and NCQA's accreditation for evaluating health plan quality.

### Conclusion: Future Directions in the Conceptual Model

Although the focus of this research is to create the tool for creating performance measures of information quality, as stated early in the discussion of the conceptual model, this merely tackles the first step in understanding how the Internet can be used as a communication vehicle for influencing health. While its importance cannot be underestimated when a majority of Americans are accessing the Internet and 25 million of them used it in 2001 as a basis for making an important personal health care decision [52], we must remember that high-quality information represents only the beginning of the chain of effective communication.

Once one can assess the performance of the information-development process and know whether the input information is of high quality, health-services researchers can return to other conceptual frameworks to explore a range of communication problems. For example, communication theory [53] offers an important way to understand how we move along the quality-of-care paradigm as well. Because good information and effective communication are almost always important prerequisites in achieving good outcomes of care, we can benefit from learning more about how we move along the communication continuum from a sender's intended message to effective action on it by a receiver.

## Conflicts of Interest

None declared.

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## Abbreviations

**HEDIS:** Health Plan Employer Data and Information Set
**NCQA:** National Committee for Quality Assurance
**URAC:** Utilization Review Accreditation Commission

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