

Breast Cancer

Pediatric Asthma

Depression

Obesity

# Proceed with Caution:

A Report on the Quality of  
Health Information on the Internet

Report Summary

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California HealthCare Foundation

Based on Findings by RAND Health

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## ACKNOWLEDGMENTS

*Proceed with Caution: A Report on the Quality of Health Information on the Internet* is a study in three parts: Report Summary, Consumer Report, and Complete Study. The Complete Study by RAND Health is augmented by charts, data, and recommendations. To receive the other reports or additional copies of this report, contact the California HealthCare Foundation's publications line at (510) 587-3199 or visit us online (<http://ehealth.chcf.org>).

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# Background

More than any other medium, the Internet has transformed the way many consumers and health care professionals find health information. This year nearly 100 million Americans will go online in search of health-related information (Harris Interactive survey, March 2001), and they are being impacted by what they read there. In fact, more than 70 percent say online health information has influenced a decision about their treatment.

People who use the Internet to find health information have access to tens of thousands of health-related Web sites and literally millions of Web pages. Consumers can readily be linked to scientific information about health problems and treatments, advertisements for physician and hospital services and pharmaceuticals, advocacy organizations, accounts of personal experiences, and opportunities to communicate online with people with similar interests.

Studies indicate that the online population is becoming more representative of the larger U.S. population in terms of race, age, income, and educational attainment. According to several recent surveys, nearly 50 percent of the Hispanic population reported using the Internet in 2000, and more than half of those reported searching for health information.

Consumers' interest in seeking health information, combined with access to the enormous amount of material available on the Web has begun to influence the way patients interact with physicians. How it will change the structure of health care delivery remains to be seen. There are both extravagant expectations and serious concerns about the trend. Some predict that ready access to the latest medical information will allow people to actively participate in their own care, and that the health status of many consumers will improve because of it. Others see the Internet as a Wild West of thousands of sites created by rugged individualists, and worry that incomplete and misleading information may directly harm consumers.

# The Need for New Research

Little has been definitively known, however, about whether the available information on the Web is sufficiently complete and accurate to support consumer decision making.

Previous studies have documented substantial variability in health-related Web site content for single diseases. Over the past year, several groups, including the American Medical Association, the Internet Healthcare Coalition, and Hi-Ethics, have become concerned with the problem of how to ensure that the health information found on the Internet is of high quality. A number of organizations have proposed, published, and voluntarily implemented criteria to guide the evaluation of health-related Web site content. However, these criteria have not been systematically applied to a broad set of Web sites and multiple medical conditions.

In response to these concerns, in July 2000, the California HealthCare Foundation commissioned RAND Health to design and conduct a comprehensive, systematic study to describe and evaluate health information available on the Internet. The project is believed to be the first to evaluate both English-language and Spanish-language search engines and Web sites.

This large-scale study addressed three questions:

1. What type of information is identified by search engines about specific health conditions and how efficient are search engines as tools for locating health information?
2. How comprehensive, accurate, and current is the information presented on selected health Web sites?

3. What is the level of literacy required to understand the information provided by these sites?

The intent of this research—to enhance the quality, efficiency, and usefulness of health information on the Internet—is similar to that of the Foundation's important January 2000 *Report on the Privacy Policies and Practices of Health Web Sites*, an in-depth examination of 21 health-related Web sites. The current study is intended to serve as a benchmark for a wide variety of future research into online content. Although its findings necessarily identify and assess individual search engines and Web sites, the study's purpose is not to point fingers, but to document weaknesses that can be improved.

The study results will be used to open a dialogue with online health content providers about ways in which they might increase the quality and accessibility of information on their sites. In addition, the findings will serve as a starting point for communication with policymakers and regulators about ways to promote better quality content on government-sponsored health sites and to safeguard online consumers. Recommendations for physicians, provider organizations, academia, consumer advocacy groups, and consumers will also be discussed. All have an important leadership role to play in creating, promoting, and using high-quality, credible, helpful health information on the Internet.

Following are some highlights of the study's methods and overall findings. A more detailed description can be found in the Complete Study, which is posted on the Foundation's Web site (<http://ehealth.chcf.org>). An article based on this study is also published in the May 23, 2001, issue of the *Journal of the American Medical Association* (JAMA, May 23/30, 2001-Vol.285, No. 20), which can be found on JAMA's Web site (<http://www.jama.org>).

# Design and Methodology

The study is divided into three sections, assessing: (1) search engine performance; (2) quality of health information on selected Web sites; and (3) the reading-grade level of online health information.

Because this study is the first large-scale attempt to document the effectiveness of search engines in helping consumers find health information, researchers designed a study model that emphasized scientific rigor. Rather than observing the experiences of typical users, they implemented a structured evaluation of specific medical conditions.

Borrowing from the logic framework of evidence-based medicine, each section of the study was conducted—in both English and Spanish—for four conditions: breast cancer, childhood asthma, depression, and obesity. These conditions were selected, in a careful winnowing process, as ones that affect diverse populations; are associated with an increased likelihood of early death and disability; and are likely to be the subject of inquiry for many consumers. Researchers noted that having accurate information on these conditions may help empower patients to be active participants in their own care.

## STUDY SECTION 1: SEARCH ENGINE PERFORMANCE

In the first section of the study, researchers set out to answer these questions:

- What are consumers likely to find when they search for specific health topics online? Does the choice of a search engine affect the results of a simple search for health information?
- How easy is it to find relevant information? Does this vary by health condition?

Ten English-language and four Spanish-language search engines were selected based on two criteria: popularity and Web site ranking method. A series of standardized searches using one simple search term for each medical condition was conducted with each search engine. The results of these searches were categorized based on the type of content found during the standardized searches.

**Table 1. Search Engines Studied**

English-Language Search Engines	Spanish-Language Search Engines
AltaVista	Quepasa
Ask Jeeves	Te Respondo
Direct Hit	Yahoo! en Español
Excite	Yupi
Google	
Goto	
Lycos	
Metacrawler	
Northern Light	
Yahoo!	

## STUDY SECTION 2: ASSESSING THE QUALITY OF HEALTH INFORMATION

The second section of the study addressed these questions:

- How comprehensive is the information on selected health Web sites?
- How accurate is it?
- How often do Web sites provide documentation that allows one to assess the source or currentness of the material?

Eighteen English-language health Web sites (seven general health and twelve condition-specific) and seven Spanish-language sites (three general health and four condition-specific) were selected. Six

English-language general health Web sites were chosen based on popularity (they were ranked highly in two widely used Internet industry reports by Cyber Dialogue and PC Data Online). Content provided by one of the most popular search engines was also included. Condition-specific English-language Web sites and all of the Spanish-language sites were selected to represent prominent examples of condition-specific sites from commercial, government, and nonprofit educational organizations.

Panels of three to four nationally recognized clinical experts and representatives from patient advocacy organizations were convened for each of the four medical conditions (breast cancer, childhood asthma, depression, and obesity). Members identified questions that would reflect the concerns of patients, their families, or laypersons seeking information on the selected conditions. They considered questions in three categories:

1. Clinical topic areas about which there is broad expert consensus and for which clear guidelines exist. (Example: Should people with suicidal thoughts seek evaluation from a doctor or emergency room?)
2. Clinical topics about which there is uncertainty. (Example: When should a woman start screening for breast cancer using mammography?)
3. Recent important developments in screening, diagnosis, or treatment of the condition. (Example: Is it wise to take fentermine/ phenfluramine for weight loss?)

A sampling of study questions related to the topic of treatments for breast cancer included:

- “Where can I get information about breast cancer clinical trials?”
- “If I have Stage I or II breast cancer, which is better treatment, mastectomy or lumpectomy plus radiation?”

Questions related to treatments for obesity included:

- “Should I consider weight-loss drugs, and if so, what prescription drugs are currently available?”
- “Who should consider weight-loss surgery? What are the risks, and how well does it work?”

See Tables A3 - A6 in the Appendix for additional evaluation questions for all four health conditions.

Based on literature reviews, the panels then developed a series of standardized answers, also known as “clinical elements” (clinical information that should be addressed) for each topic and question. For example, three standardized answers related to antidepressant medication were developed:

- Antidepressant medications typically begin to work within several weeks. However, many patients do not experience substantial benefits for four to eight weeks, and it may take three to four months before patients taking antidepressants feel completely better.
- Patients with a single episode of acute depression who experience initial improvement should continue to take the medication, usually for six to twelve months after they feel completely better to keep feeling well.
- With antidepressant medications, many people have some side effects early in treatment (in the first four to six weeks); most side effects get better in the first month; for some people, the side effects can be bad enough to stop the medicine. Common side effects include anxiety, sexual dysfunction, sleepiness, trouble sleeping, weight gain/loss, restlessness, and nausea.

**Table 2. Web Sites Included in Evaluation of Quality**

<b>English-Language Web Sites</b>	<b>URL</b>
<b>Popular General Health</b>	
Allhealth.com	www.allhealth.com
CBS Health Watch	www.cbshealthwatch.com
DrKoop.com	www.drkoop.com
Intelihealth	www.intelihealth.com
Onhealth	www.onhealth.com
WebMD	www.webmd.com
Yahoo!	www.yahoo.com
<b>Condition-Specific</b>	
American Academy of Allergy, Asthma, & Immunology	www.aaaai.org
American Cancer Society	www.cancer.org
American Obesity Association	www.obesity.org
Athealth.com	www.athealth.com
Cancernet	www.cancernet.gov
Depression.com	www.depression.com
MyAsthma	www.myasthma.com
National Heart, Lung, and Blood Institute	www.nhlbi.nih.gov
National Institute of Mental Health (NIMH)	www.nimh.nih.gov
National Library of Medicine	www.nlm.nih.gov
Obesity Online	www.obesity-online.com
Oncolink	www.oncolink.com
<b>Spanish-Language Web Sites</b>	
<b>Popular General Health</b>	
Graciasdoctor	www.graciasdoctor.com
Salud	www.salud.com
Salud Latina	www.saludlatina.com
<b>Condition-Specific</b>	
Cancernet	www.cancernet.gov
Centro Peso	www.centropeso.com
National Institutes of Health	www.nih.gov
New York Online Access to Health	www.noah-health.org

To assess the ability of consumers to arrive at the necessary information contained in the standardized answers, two searchers visited each selected Web site looking for information related to the questions. The results from each search were saved with special software. Site identifiers were removed

to ensure a blinded review, and the materials were assembled into separate notebooks and sent for expert review. Four rating forms were developed to help standardize the evaluation of the information.

### **STUDY SECTION 3: READABILITY ASSESSMENT OF HEALTH INFORMATION**

The third section of the study addressed the following question: At what reading grade level do these Web sites provide their information?

Researchers applied widely accepted readability formulas to randomly selected passages of text from both English- and Spanish-language Web sites. These formulas measure grade levels as a function of the average sentence length and word complexity in text samples.

### **DESIGN LIMITATIONS**

Although this large-scale study adhered to a rigorous scientific protocol, and its conclusions are authoritative, it is important to note certain design limitations.

First, the Internet changes constantly, and researchers were only able to study it at one point in time.

Second, they looked at a small sample of search engines and conditions, and hence cannot draw more general conclusions about the performance of all search engines and information on all conditions. However, the most popular search engines were included, and the results should reflect what most people experience.

Third, the performance of search engines was studied using very simple search terms describing the medical condition; the findings regarding the efficiency of search engines in yielding relevant content might have been quite different if more sophisticated search strategies were employed.

Finally, because the researchers did not use actual consumers to search for information and test their knowledge after such a search, they cannot draw conclusions about what consumers actually encounter or how well they are able to judge the quality of the information they find. However, the systematic nature of the research methods provides a backdrop for future studies of actual consumer behavior; researchers can compare what consumers are able to find with what is actually out there to find.

# Findings

## **Finding 1: Search engines are inefficient tools for locating relevant health information.**

The abundance of information available to consumers is one of the major attractions of the Internet as a means for obtaining health information, but consumers must sift through a lot of irrelevant material during their searches. The efficiency with which relevant information can be located varies significantly across search engines and conditions.

Furthermore, it is unclear how consumers can discern which sites and what information are most relevant and accurate. Specific findings include:

- *Few searches lead to relevant health information.* When using English-language search engines, Internet users have a one in five chance of finding information pertinent to their search. Users of Spanish-language search engines have only a one in nine chance of finding such information.

A typical search produced a list of 93 links, about one-third of which were “relevant” (contained the search term or a related word in the title). Among the English-language search engines studied, AltaVista, Direct Hit, and Metacrawler produced higher-than-average proportions of relevant links, while Excite and Northern Light produced lower proportions. On average, only three in five of these links reached information related to the search. Relevant links found using Northern Light and Google were significantly more likely to reach information related to the search; relevant links found using Direct Hit, Goto, and Altavista were significantly less likely to reach information related to the search.

When using Spanish-language search engines, Internet users have an overall one in nine chance of finding information that is perti-

nent to their search. A typical search produced a list of 105 links, less than one-fifth of which were relevant. Yahoo! Español produced higher than average proportions of relevant links, while Yupi produced lower proportions. On average, only three in five of these relevant links reached information related to the search. Relevant links found using TeRespondo were significantly more likely to reach information related to the search; relevant links found using Quepasa were significantly less likely to reach information related to the search.

Even when links led to information pertinent to the search, it required more than one click to find this information in almost half the time. Cyber Dialogue reports that more than half of consumers who use search engines to find health information spend about a half-hour on such searches, so efficiency and the relevance of information retrieved are important aspects of search engine performance.

- *Different search engines take you to different places.* Search engines are not interchangeable; the results of a search vary markedly depending on which one is used. On average, only 11 percent of Web sites found by a typical English-language search engine appeared on the top-ten list of another search engine.
- *Health information on the Internet is commercialized.* About half of the information that Internet users are likely to find using English-language search engines contains material that is promotional (i.e., sells products or services), but is not clearly labeled as an advertisement.

One-fifth of the information that Internet users are likely to find using Spanish-language search engines contains material that is promotional but is not clearly labeled as an advertisement.

It is important to note that half of consumers who use search engines to find health information spend about a half-hour on such searches, according to CyberDialogue; therefore, efficiency and the relevance of information retrieved are vital aspects of search engine performance.

**Finding 2: Answers to important questions that consumers should be able to find are often incomplete, although when information is provided it is generally accurate.**

Most sites that were studied provided at least minimal coverage of 70 percent of the clinical topic areas looked for. Some sites, however, offered very little information, with up to 70 percent of clinical topic areas completely uncovered. Only four of the English-language Web sites studied and none of the Spanish-language ones offered more than minimal coverage for at least 80 percent of the clinical topic areas.

Given the poor overall performance when both coverage and accuracy are considered, and the substantial variation in performance across conditions and Web sites, these results suggest that consumers using the Internet have a difficult time finding information on a health problem. More importantly, if people rely on the Internet to guide their decisions about when to get care, these failures could have serious consequences. A few specific findings in this section of the study:

- Information that medical experts and consumer advocates thought were important for consumers to be able to find were not found on the English-language sites studied about one-fourth of the time, and more than minimal coverage was found for only half of these topics. Some of the gaps were striking. For example, only a few sites indicated that a woman with a persistent breast mass and a negative mammogram usually needs further evaluation. Less than half of the Spanish-language materials explained that mastectomy and lumpectomy plus radiation are equivalent treat-

ments for early-stage breast cancer. Almost no sites provided information about signs of a life-threatening asthma episode, and few sites indicated that persons with suicidal thoughts should seek care promptly.

- Spanish-language health information is sparse and is less consistently accurate. On Spanish-language Web sites, no coverage was found for half of studied health topics, and more than minimal coverage was found for only one topic in four.
- Nearly two-thirds of the English-language materials list a date and author, and about half of materials with dates were updated within the past year. Only one-sixth of the Spanish-language materials lists a date and author, and almost half of all Spanish-language materials show neither an author nor a date.
- Although the accuracy of information presented was fairly high, more than half of the sites revealed one or more conflicts of a clinically important nature, such as about a treatment choice. For example, a childhood asthma Web site reported in one place that using inhaled steroids does not stunt growth in children, and elsewhere it reported that using inhaled steroids does stunt growth in children.
- As seen in Table 3, breast cancer topic areas were covered more often than the other studied conditions on the English-language Web sites examined. Topics that were covered most often included information related to breast cancer screening: “No one in my family has breast cancer. Do I still need breast exams and mammograms? When should I start having regular mammograms? Do I need one every year?” Topic areas related to childhood asthma and obesity were covered significantly less often than the other two conditions on the English-language Web sites studied. Topics that were covered least often on these sites included symptoms suggestive of poorly controlled

**Table 3. Percentage of Clinical Topic Areas Receiving More Than Minimal Coverage with Complete Accuracy by Condition**

Condition	Average across English-Language Sites Studied	Average across Spanish-Language Sites Studied
Breast Cancer	63%*	39%*
Childhood Asthma	36%†	23%
Depression	44%	12%†
Obesity	37%†	15%

\* Statistically better performance than condition average within the same language ( $p \leq .05$ ).

† Statistically lower performance than condition average within the same language ( $p \leq .05$ ).

asthma and the safety and effectiveness of dietary supplements for treatment of obesity. See Appendix for further data.

As shown in Table 4, two English-language sites provided more than minimal coverage of their topic areas with complete accuracy significantly more often than average sites addressing those same conditions. Oncolink performed significantly better than average among breast cancer sites and NIMH performed significantly above average among depression sites. There were three instances in which the content found on a site was significantly below average by this measure. No Web site performed statistically better than average for either childhood asthma or obesity.

**Finding 3: Most Web-based health information is difficult for the average consumer to understand.**

A variety of studies have shown that health-related information is more difficult to comprehend than most other types of information, that the reading ability of patients varies widely and is generally

lower than the level of school they have completed, and that patients often have difficulty understanding written health information. One study of English-speaking diabetic patients found that while 60 percent could understand information written at the sixth-grade level, only 21 percent could understand information written at the ninth-grade level.

The study found that:

- Most health Web sites are written at reading levels that exceed the abilities of many consumers, especially underserved populations.
- Half of the English-language materials are written at the college level and all were at least at the tenth-grade reading level.
- Forty percent of the Spanish-language materials are written at the college level and almost all were written at least at the ninth-grade reading level.

**Table 4. Percentage of Clinical Topic Areas Receiving More Than Minimal Coverage on English-Language Sites Studied, with Complete Accuracy by Site**

Condition	Statistically Better than Condition Average	Statistically Worst than Condition Average	Condition Average across Sites Studied
Breast Cancer	Oncolink (85%)	Yahoo! (27%)	63%
Depression	National Institute of Mental Health (73%)	All Health (13%)	44%
		Yahoo! (13%)	

# Recommendations

The study, while identifying some very serious weaknesses (and potential hazards) in Web-based health information sources for consumers, suggests opportunities for enriching the information environment and safeguarding patients. Responsibility and leadership from all marketplace participants, including consumers, are needed to accomplish this. Below are specific recommendations for each group.

## **HEALTH WEB SITE CONTENT PROVIDERS:**

1. Commission clinical panels of experts to review coverage, accuracy, and factual conflicts before putting material online.
2. Work with consumer advocacy organizations to make sure that frequently asked consumer questions are addressed and that language used is lay-friendly.
3. Provide information at the sixth-grade reading level on consumer-oriented sites. Currently, the U.S. Department of Health and Human Services recommends that patient education materials not exceed that reading level.
4. Provide for systematic review of clinical content by experts, and incorporate a requirement for such review into standards for quality assessments of health-related sites. There are four major private-sector efforts to improve the quality of health sites: Health on the Net (HON), Hi-Ethics, eHealth Ethics Initiative, and the AMA Guidelines. Although most of the proposed frameworks address the issue of quality, only the AMA guidelines call for systematic review of clinical content by experts. Reviews should be undertaken by an independent party that is unrelated to the

health information provider and that does not provide such information itself.

5. Incorporate readability standards into overall quality assessments of health-related Internet sites. (Standards are not currently included in quality assessments such as the HON code.) Readability assessments should be made on a regular basis and disclosed to consumers choosing among health Web sites. Assessments should be made on Spanish- and English-language Web sites and the results published and disseminated in both languages. Methods of assessing readability should be disclosed.
6. Consider consolidation and collaboration among information providers, because a small number of high-quality health information providers can serve a vast population if acceptable standards of readability and translation are achieved.
7. Develop standards for ensuring information is up-to-date. Web pages could be “date stamped” to allow users to determine when the information was most recently updated. A more stringent standard would have Web pages “expire” if they have not been updated within a certain timeframe.

## **CONSUMER AND SPANISH- SPEAKING ADVOCACY GROUPS:**

1. Help consumers by “adopting” one or two relevant sites and continually screening their content for coverage and accuracy. Develop arrangements between content providers and advocacy organizations who could arrange for impartial review by experts.
2. Press for improvements in site content and presentation to make information more complete, accurate, and accessible, and by referring consumers to the best sites.

3. Use this study's documentation of disparity between Spanish-language and English-language sites (Spanish-language sites are fewer in number and provide less complete information) to call for action in the areas of education, awareness, and translation needed to achieve parity.

#### **HEALTH CARE PROVIDERS:**

1. Help patients distinguish between useful and non-useful Web sites. Recommend condition-specific sites that may be useful to groups of patients. Consider setting up a simple Web site with links to appropriate and credible sites, and notify categories of patients by e-mail when relevant disease-specific information becomes available on the Web. Utilize the Web as a time-saver for both physicians and patients so that face-to-face visits are better spent.
2. Emphasize to patients the critical role that physicians must play in examining patients, making a diagnosis, and recommending treatment.
3. Work through professional societies to organize physicians, pharmacists or a whole new group of professionals to provide a more formal interpretive function. In the current health business environment, this may require attention to the mechanisms by which such services could be reimbursed.
4. Work through specialty societies to provide key clinical content for Web sites, similar to the way these societies have become involved in developing and promulgating guidelines. Their participation in writing and approving clinical content on the Web could significantly improve the coverage, accuracy, and presentation of the material. Specialty societies should work with advocacy organizations to

ensure that the material they develop addresses important patient concerns and facilitates patient decision making around when to seek medical care.

#### **POLICYMAKERS AND REGULATORS:**

1. Continue to fund high-quality sites, especially for underserved consumer audiences.
2. Support constituents (of 100 million-plus Internet users, 70 percent seek health care information) by advocating high quality, reliable, and accessible content.
3. Address poorer availability and quality of Spanish-language sites by translating and culturally adapting what is currently available on English-language sites.
4. Effectively publicize and increase access to high-quality government sites.
5. Fund research on effective communication of health information online to populations with a wide range of reading levels.

#### **CONSUMERS:**

1. Improve ability to navigate successfully through the online territory by setting aside adequate time for searches, and visiting several sites.
2. Be aware that sites will not necessarily provide a comprehensive picture of what is needed to know about a condition. These sites can only supplement consultation with health care professionals.
3. Be skeptical of sites that are not well-known or government sponsored, because many are created and maintained for commercial reasons. The information on these sites may be

accurate, but it is wise to consider the possibility that someone is trying to sell something by providing the information.

4. Ask health care professionals for help in understanding conflicting or difficult-to-comprehend information, especially when it concerns conditions or treatment decisions.

A key challenge across all of these recommendations is the extent to which the market for health information will reward those who provide the highest quality material. This is parallel to the problems faced in the health care delivery system—where focus is frequently on cost rather than quality. As the business environment for the Internet evolves, it will serve the public well if mechanisms are developed to sort the higher-quality from the lower-quality information providers. The solutions may have to come from cooperation between government and the not-for-profit sector, including consumer advocacy organizations, trade associations, professional societies, and others whose purposes are aligned with serving the public interest. Ultimately, everyone will benefit from the easy availability of better health information online.

The Internet, while still in its formative stage, is developing a powerful influence on consumers in addressing their health questions. Whether the influence will be almost entirely beneficial—and at the very least, benign—is up to the market participants to determine.

# Focus on eHealth and Quality

This study is one in a series of activities the California HealthCare Foundation has undertaken to enhance the role the Internet can play in improving health care quality, delivery, and access.

The Foundation's eHealth Program is working to stimulate the adoption and effective use of new information technologies and to increase the understanding of policymakers and industry leaders of emerging ehealth policy and regulatory issues. The Foundation's Quality Initiative focuses on encouraging and engaging consumers to be more active participants in their care and heighten the importance of quality as a consideration when they choose and use care.

The following are a few highlights from this work:

- *A Primer on Physician Order Entry*—Designed for hospital leadership, this is a basic overview of Computerized Physician Order Entry (CPOE), its potential for reducing medication errors within a hospital setting, and the cultural, financial, and operational considerations surrounding its implementation (<http://quality.chcf.org/view.cfm?itemID=3315>).
- *eHealth Reports*—A series of reports, surveys, and forecasts that describe emerging concepts and trends in the ehealth space (<http://ehealth.chcf.org>).
- *Health-e-App*—A Web-based application developed to streamline the enrollment of low-income children and pregnant women in California's Medicaid (Medi-Cal) and Children's Health Insurance (Healthy Families) programs (<http://www.healthapp.org>).
- *Health Privacy*—A series of initiatives including: a national survey to assess consumer attitudes; *Report on the Privacy Policies and Practices of Health Web Sites*; a Promoting Health/Protecting Privacy primer and, in partnership with Consumer's Union, several health privacy briefings and a statewide conference (<http://ehealth.chcf.org/index.cfm?section=Privacy>).
- *Santa Barbara County Care Data Exchange*—A community-wide effort to build a real-time, patient-centric system for the exchange of health care information to improve the efficiency, quality, and safety of care ([http://www.carescience.com/healthcare\\_providers/care\\_data\\_exchange.shtml](http://www.carescience.com/healthcare_providers/care_data_exchange.shtml)).
- *Voices of Experience: Case Studies in Measurement and Public Reporting of Health Care Quality*—A compendium of collaborative projects involving consumers, purchasers, and providers, which have advanced the quality agenda in their communities (<http://quality.chcf.org/view.cfm?section=Measures&itemID=3865>).

# Appendix

**Table A1: Coverage and Accuracy of Selected Health Topics on English-Language Web Sites**

ENGLISH-LANGUAGE WEB SITES	Average Percentage of Clinical Elements by Web Site (%)			
	More than Minimal Coverage and Completely Correct	More Than Minimal Coverage	Minimal Coverage	No Coverage
<b>Breast Cancer (Overall*)</b>	<b>63†</b>	<b>67†</b>	<b>17</b>	<b>16†</b>
Oncolink.com	85†	90†	7	3†
Cancernet.nih.gov	80	84	10	6
Webmd.com	80	82	14	4
Cancer.org	73	73	18	10
Drkoop.com	69	69	12	20
Onhealth.com	68	74	18	9
Intelihealth.com	53	61	22	18
Allhealth.com	47	55	22	24
CBSHealthWatch.com	45	47	25	27
Yahoo.com	27‡	31‡	29	39‡
<b>Childhood Asthma (Overall*)</b>	<b>33‡</b>	<b>43‡</b>	<b>30</b>	<b>27</b>
NHLBI.nih.gov	52	55	25	20
Myasthma.com	44	47	30	23
Drkoop.com	43	53	26	21
Onhealth.com	42	52	31	16
Intelihealth.com	38	41	27	32
Webmd.com	36	50	36	14
CBSHealthWatch.com	31	44	28	28
Aaai.org	26	32	35	32
Allhealth.com	22	23	27	51‡
<b>Depression (Overall*)</b>	<b>44</b>	<b>53</b>	<b>27</b>	<b>20‡</b>
NIMH.nih.gov	73†	81	19	0
Intelihealth.com	65	68	19	13
Webmd.com	56	60	30	10
CBSHealthWatch.com	52	57	27	17
Depression.com	48	56	27	18
Drkoop.com	44	48	33	20
Onhealth.com	41	62	21	18
Athealth.com	35	46	37	18
Allhealth.com	13‡	40	33	23
Yahoo.com	13‡	17‡	22	58

**Table A1: Coverage and Accuracy of Selected Health Topics on English-Language Web Sites (continued)**

ENGLISH-LANGUAGE WEB SITES	Average Percentage of Clinical Elements by Web Site (%)			
	More than Minimal Coverage and Completely Correct	More Than Minimal Coverage	Minimal Coverage	No Coverage
<b>Obesity (Overall*)</b>	<b>37†</b>	<b>40‡</b>	<b>25</b>	<b>35‡</b>
CBSHealthWatch.com	59	60	19	21
Intelihealth.com	52	57	23	20
NLM.nih.gov	51	53	17	30
Webmd.com	42	43	30	27
Obesity.org	40	43	14	42
Drkoop.com	39	42	38	20
Onhealth.com	30	31	42	27
Allhealth.com	27	28	33	39
Obesity-online	27	34	11	54‡
Yahoo.com	7	10	20	70‡
<b>Overall Average</b>	<b>45</b>	<b>51</b>	<b>25</b>	<b>25</b>

\* Weighted by number of reviews. Overall scores are an average of un-rounded scores, and therefore do not correspond exactly to the average of rounded site scores.

† Significantly better performance than condition average (p<0.05)

‡ Significantly lower performance than condition average (p<0.05)

**Table A2: Coverage and Accuracy of Selected Health Topics on Spanish-Language Web Sites#**

SPANISH-LANGUAGE WEB SITES	Average Percentage of Clinical Elements by Web Site (%)			
	More than Minimal Coverage and Completely Correct	More Than Minimal Coverage	Minimal Coverage	No Coverage
<b>Breast Cancer (Overall*)</b>	<b>39†</b>	<b>39†</b>	<b>12</b>	<b>49</b>
Cancernet.nih.gov	76	76	3	21
Salud.com	43	44	10	46
Saludlatina.com	21	21	12	68
Graciasdr.com	20	20	20	61
<b>Childhood Asthma (Overall*)</b>	<b>23</b>	<b>27</b>	<b>40</b>	<b>33†</b>
NIH.gov	30	34	34	33
Salud.com	26	27	45	28
Saludlatina.com	16	19	41	41
Graciasdr.com	13	23	44	33
<b>Depression (Overall*)</b>	<b>15</b>	<b>15‡</b>	<b>25</b>	<b>60</b>
Salud.com	24	26	10	63
Noah.edu	15	17	30	54
Graciasdr.com	5	11	29	58
Saludlatina.com	2	7	19	73
<b>Obesity (Overall*)</b>	<b>15</b>	<b>14</b>	<b>15</b>	<b>69‡</b>
Salud.com	22	22	25	53
Saludlatina.com	17	17	3	80
Graciasdr.com	15	18	14	68
Centropeso.com	10	10	18	73
<b>Overall Average</b>	<b>22</b>	<b>24</b>	<b>23</b>	<b>53</b>

# Differences among sites within condition were not statistically significant.

\* Weighted by number of reviews. Overall scores are an average of un-rounded scores, and therefore do not correspond exactly to the average of rounded site scores.

† Significantly better performance than condition average ( $p < 0.05$ )

‡ Significantly lower performance than condition average ( $p < 0.05$ )

**Table A3: Evaluation of Breast Cancer Information on English-Language Web Sites**

BREAST CANCER		Average Percentage (%) of Selected Condition-Related Topics for 10 English-Language Web Sites				
		Coverage			Accuracy	Combined
Condition-Related Topic	Corresponding Consumer Question	No Coverage	Minimal Coverage	More Than Minimal Coverage	Completely Correct	More Than Minimal Coverage and Completely Correct
1. Risk assessment and use of tamoxifen for risk reduction	Are there any medications I can take to reduce my risk of getting cancer?	10%	12%	78%	89%	73%
2. Screening	No one in my family has had breast cancer. Do I still need breast exams and mammograms? When should I start having regular mammograms? Do I need one every year?	10%	11%	79%	86%	69%
3. Evaluation of a palpable breast mass	I have a lump in my breast. What should be done to check this?	18%	25%	57%	93%	57%
4. Treatment	If I have Stage I or Stage II breast cancer, which is better treatment: mastectomy or lumpectomy plus radiation? Where can I get information about breast cancer clinical trials?	13%	14%	73%	92%	70%
5. Alternatives to standard surgical and medical therapies	What alternative therapies (such as acupuncture, herbs or homeopathy) can help me fight breast cancer?	28%	23%	49%	96%	49%

**Table A4: Evaluation of Childhood Asthma Information on English-Language Web Sites**

CHILDHOOD ASTHMA		Average Percentage (%) of Selected Condition-Related Topics for 9 English-Language Web Sites				
		Coverage			Accuracy	Combined
Condition-Related Topic	Corresponding Consumer Question	No Coverage	Minimal Coverage	More Than Minimal Coverage	Completely Correct	More Than Minimal Coverage and Completely Correct
1. Symptoms	What are the common symptoms of asthma in children?	33%	26%	41%	89%	36%
2. Poorly controlled asthma	I have been told by a doctor that my child has asthma. S/he has difficulty breathing at night and uses an inhaler everyday. Does this mean that my child's asthma is not well controlled?	48%	29%	23%	72%	18%
3. Therapies and adverse effects	What should I do about my child's asthma, especially if it is not well controlled? Are there any medicines or special equipment that my doctor can prescribe? Do they have any side effects?	13%	22%	65%	76%	48%
4. Initial management of severe asthma	How do I know if my child is having life-threatening symptoms? What should I do?	33%	46%	21%	84%	19%
5. Risk factors	Could certain exposures in the indoor and/or outdoor environment have caused or made my child's asthma worse? What can be done to identify, eliminate or diminish factors in the environment that can worsen my child's asthma symptoms?	29%	32%	39%	84%	33%
6. Etiology	What causes asthma? Is it curable?	32%	22%	46%	98%	46%
7. Expectations from therapy	What should I expect from my child's asthma treatment?	23%	41%	36%	90%	36%

**Table A5: Evaluation of Depression Information on English-Language Web Sites**

DEPRESSION		Average Percentage (%) of Selected Condition-Related Topics for 10 English-Language Web Sites				
		Coverage			Accuracy	Combined
Condition-Related Topic	Corresponding Consumer Question	No Coverage	Minimal Coverage	More Than Minimal Coverage	Completely Correct	More Than Minimal Coverage and Completely Correct
1. Symptoms	I've been feeling a little sad lately. How do I know if I'm depressed?	13%	15%	72%	82%	61%
2. Treatment	What are the most effective treatments for depression?	17%	11%	72%	68%	56%
3. Anti-depressant medications	If my doctor recommends an antidepressant medication for the treatment of my depression, how long should I take it for? What should I expect and when will I start to feel better?	16%	17%	67%	78%	55%
4. Role of Counseling	When should I consider psychological counseling instead of or in addition to medication?	31%	29%	40%	73%	33%
5. Suicidal ideation	I feel so depressed I've thought about suicide. What should I do?	12%	46%	42%	84%	37%
6. Evaluation	Who should I see for evaluation and treatment of my depression? A primary care doctor, a psychiatrist or a psychologist/therapist?	33%	54%	13%	71%	8%
7. Etiology	What causes depression?	0	3%	97%	90%	87%

**Table A6: Evaluation of Obesity Information on English-Language Web Sites**

OBESITY		Average Percentage (%) of Selected Condition-Related Topics for 10 English-Language Web Sites				
		Coverage			Accuracy	Combined
Condition-Related Topic	Corresponding Consumer Question	No Coverage	Minimal Coverage	More Than Minimal Coverage	Completely Correct	More Than Minimal Coverage and Completely Correct
1. Definitions and indications for weight loss	How do I know if I need to lose weight?	36%	16%	48%	78%	42%
2. Health risks	What are the health risks of being overweight/obese?	12%	29%	59%	90%	56%
3. Risks and benefits of popular diets	What should I consider before starting on a low carbohydrate, high protein, high fat diet like the Atkins plan?	49%	34%	17%	87%	17%
4. Physical activity/prevention	What is the value of physical activity for (a) promoting weight loss, (b) maintaining weight at current levels, and (c) for general health?	20%	34%	46%	94%	43%
5. Medications endorsed for weight loss	Should I consider weight-loss drugs, and if so, what prescription and non-prescription drugs are currently available?	47%	25%	28%	83%	25%
6. Surgery	Who should consider weight loss surgery, what are the risks, and how well does it work?	32%	22%	46%	85%	44%
7. Safety and effectiveness of dietary supplements	Can herbal supplements containing ephedrine plus caffeine help me to safely lose weight?	61%	19%	20%	96%	19%