Setting the Public Agenda For Online Health Search

A White Paper and Action Agenda

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ABOUT URAC

URAC, an independent, nonprofit organization, is a leader in promoting health care quality through accreditation and certification programs. URAC's standards keep pace with the rapid changes in the health care system, and provide a mark of distinction for health care organizations to demonstrate their commitment to quality and accountability. Through its broad-based governance structure and an inclusive standards development process, URAC ensures that all stakeholders are represented in setting meaningful standards for the health care industry.

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URAC and Consumer WebWatch thank the many participants in this process. We note that the recommendations in this document reflect statements made at the stakeholder meetings and in subsequent exchanges about this white paper. Participants had the opportunity to review and comment on the recommendations but were not asked to vote on them. Therefore the recommendations do not reflect endorsement by any particular individual or the organizations with which they are associated.
Searches for health information are one of the most common reasons that consumers use the Internet. Both consumers and quality experts have raised concerns about the quality of information on the Web and the ability of consumers to find accurate information that meets their needs. Researchers have found that the processes by which consumers locate health information on the Internet, and the evaluations they make regarding which Web sites to visit, are important variables in the quality of information they ultimately view and use.

It is of great importance to understand factors influencing online searches for health information and to develop technical and educational approaches for maximizing quality and benefit of health searches.

URAC and Consumer WebWatch (CWW), a project of Consumers Union, undertook this project to examine factors influencing the results of online health searches, and to develop an agenda for future research and development that would improve the results of health searches. We reviewed published literature and industry reports, and convened two “stakeholder groups,” consisting of consumers, quality experts, search engine experts, researchers, providers, informatics specialists and others. Meeting participants reviewed existing information and developed recommendations for additional research, technical improvements, and educational approaches needed to improve the results of online consumer searches for health information. Participants reviewed the recommendations after the meeting and had the opportunity to comment, but were not asked to vote on or endorse the recommendations.

For the purposes of this project we assumed that most searchers would prefer information that is accurate, reliable and complete. This was our working definition for “quality” Web sites. Other elements of quality, such as reading level and comprehensiveness may vary depending on the user and the user’s needs at a given time.

The outcomes of consumer searches for health information are influenced by a number of variables. The project was based on the premise that the more we know about these variables, the better we can design educational and technical strategies that help consumers get to the information they seek. Some of these factors include:

**Consumer Behavior:** Who searches, how do they search, what health terms do they search for, and what level of information do they want? How do they evaluate the information they find on the Web? How closely does the information that searchers find match their expectations and meet their information needs? What do they do once they have found information on the Web?

**Web Site Behavior:** How do sites ensure the integrity and quality of information they post? Is the information presented in a format and style that consumers can understand and use? Can Web site content be marked in such a way to indicate comprehensiveness, intended audience or other factors to help match sites with the needs of specific users? Could the Web site be located by a search engine?

**Search Engines:** How well do they understand what health information consumers are looking for? What mechanisms do they have to adapt health searches to diverse users’ needs such as high and low literacy levels? How can search engines be constructed to more effectively index health information and differentiate between high quality sites and those of lesser quality? Can search engines be refined to intuit consumer needs or “learn” from prior searches?

The URAC/CWW stakeholder groups made a number of recommendations addressing both research needs and actions that could be implemented by some or all of the groups interested in improving the results of health searches. Some recommendations are based on current evidence of effectiveness, while others are based on expert opinion and have less evidence to support them.
The group’s recommendations cut across many issues and organizations. This suggests a need for additional collaboration among organizations with a stake in improving health information, and one or more organizations willing to serve as a convener for future work on this issue.

Recommendations

Leadership for Health Search Improvement

- Organizations concerned about the quality and accessibility of health information online should continue to collaborate to promote “health search literacy.”
- Collaborators should convene a leadership summit on health search literacy to discuss feasibility and implementation of many of the recommendations in this paper.

Collaborating organizations should...

- Work with funding organizations to develop a comprehensive long term research agenda to improve health searches and increase access to quality health information.
- Develop enhanced research methodologies to evaluate the quality, impact and effectiveness of online health information.

Consumer Directed Tools

- Create tools to support consumer health information needs, including preset, prescreened health bookmarks and more guidance on how to reach health gateways and portals containing trusted health content.
- Develop and circulate a public domain brochure on health search strategies that could be branded and distributed by physicians, employers, health plans, and others to educate consumers.
- Develop public domain interactive, validated search strategy content pages that could be branded and used by health Web sites.

Research Needs

- Identify the search needs and capabilities of diverse populations of searchers, including culturally-diverse users and searchers with health needs of differing intensity and severity.
- Develop more understanding about how consumers interpret online health information, assess its credibility, and make health-related decisions.
- Research the relationship between consumer search strategies and consumer expectations for results to determine effective approaches for conveying information on the Internet.
- Research factors affecting physician assessments of Web based information and how quality content affects physician recommendations to patients about online health information resources.
- Assess the relationship between expert accreditation, quality seals, ratings and content quality, as well as the impact of such endorsements on both consumer behavior and Web site behavior.
- Research the correlation between Web site traffic volume and consumer satisfaction, particularly for health Web sites where there is variation in dimensions of quality such as accuracy, comprehensiveness, ease of navigation and reading level.
- Evaluate content quality of Web sites in different domains, (e.g. .gov, .edu, .com, and .org) to identify similarities and differences related to quality within and across categories of Internet domain names.
- Evaluate the impact of Internet-based health information on health outcomes: utilization, behavior change, knowledge, burden of illness and disease, or other measures.
- Research the relative effect of each component of a search algorithm (word frequency and placement, links, etc) for finding health information.
- Validate elements of some search algorithms, such as link frequency, as indicators of value/quality.
- Conduct periodic studies to monitor changes in accuracy and quality of content over time, including updating findings from the seminal RAND study.

Education Agenda

- Develop models for offering health search education at teachable moments and in diverse consumer settings.
- Promote dissemination of existing educational tools and resources to assist consumers in evaluating health information on the Web more effectively.
- Develop user-appropriate tools and approaches to

"Research factors affecting physician assessments of Web based information and how quality content affects physician recommendations to patients about online health information resources."
assist Internet users with special needs. High priority user groups may include disabled, low literacy, and non-English speaking groups.

- Urge provider organizations to educate provider members on the value of offering Internet information and interactive learning recommendations as part of the therapeutic intervention.
- Educate health Web site developers on how to make information findable and how to meet the content-level of their intended users.
- Urge education organizations, in collaboration with health organizations, to develop a school-based or publicly available health search curriculum.

Technology Improvement Agenda

- Continue to develop interactive features on search engines and sites to customize and personalize health searches.
- Develop more functionality for search engines to enhance selected health queries by offering additional relevant information.
- Develop technological markers or indicators that could be uniformly applied by Web site developers to indicate accuracy and comprehensiveness of health Web sites.
- Develop codes to indicate when information on a Web site “supercedes” previous information.
- Develop collaborations between health quality and search engines experts to develop codes for validated quality proxies.
- Develop search technology similar to that used in the commercial sector to direct consumers to related, relevant information based on both searching and viewing behaviors.
- Enhance personalized searches by building search engine capability to “learn” from repeated searches and user behavior.

Expanding the Market for Quality

- Develop a health equivalent of “bizrate” or “ebay” surveys that can be used by consumers to evaluate Web sites after viewing.
- Sponsor a competition for individuals or organizations to design a search algorithm that returns the most credible health results as evaluated by experts. Design a separate contest for the most effective business plan to make the business case for building quality factors into health searches.
2.1 The Importance of Finding Quality Information on the Web

Searches for health information are one of the most common reasons that consumers use the Internet. According to a 2003 report from the Pew Internet & American Life Project, 62% of Americans with Internet access have used the Web to get health or medical information, and about 6% of Internet users search for health or medical information on an average day. The Internet has transformed the ability of consumers to find health information and to connect with other individuals with similar interests. The importance of the Internet as a source of health information has been recognized by the federal government, which established a series of goals relating to access and quality of information on the Internet in the Healthy People 2010 action plan.

This newfound capability to access health information on the Internet has the potential to dramatically influence consumers' health care and lifestyle choices. However, the increased access to Web-based information has also raised concerns about the quality of information consumers are using, as well as the impact of this information. Disparities in access to information have also become apparent. These factors suggest the need to better understand how consumers find health information on the Web, how to evaluate the quality of information retrieved, and how to help consumers to critically evaluate and manage information.

In fact, research on health Web sites has raised some concerns about the quality of information located on the Web. Health information Web sites are highly diverse, ranging from professional to commercial to personal. Sites are not always updated regularly, potentially leading to confusion when conflicting or incomplete information is retrieved in a health search. A 2001 study by RAND for the California Healthcare Foundation showed that information on health Web sites is often incomplete or out of date. Uneven quality of information might be of little concern if consumers routinely consulted health care professionals about the results of their information searches. However, Pew found that when consumers do access health information on the Web via a search engine, 69% percent do not later discuss the information they found with a doctor or nurse.

Search engines and directories play a central role in facilitating access to online health information. According to the Pew Internet & American Life project, 81% of consumers seeking health information online do so through a search. For many people, search engines are the main source of guidance to locate information that they use to help make personal health decisions. The criteria used to identify and rank health-related Web sites vary among search engines, and often is not apparent to consumers. Search results may be affected by the structure of content on health Web sites, consumer search terminology, and the use of paid placements by the search engine.

In short, research on health searches suggests that the process by which consumers locate health information on the Internet, and the evaluations they make regarding which Web sites to review are important variables in the quality of information they ultimately view and use. Thus, it is of great importance to understand factors influencing online searches for information and to develop technical and educational approaches for maximizing quality and benefit of health searches.

2.2 About the Health Search Project

In 2003, URAC and Consumer WebWatch (CWW), a project of Consumers Union, undertook this project to examine factors influencing the results of online health searches, and to develop an agenda for future research and development that would improve the results of health searches. We reviewed published literature and industry reports, and convened two “stakeholder groups,” consisting of consumers, quality experts, search engine experts, researchers, providers, informatics spe-
cialists and others. Meeting participants reviewed existing information and developed recommendations for additional research, technical improvements, and educational approaches needed to improve the results of online consumer searches for health information. Participants reviewed the recommendations after the meeting and had the opportunity to comment, but were not asked to vote on or endorse the recommendations.

For the purposes of this project we assumed that most searchers would prefer information that is accurate and reliable. These attributes are also components of effective health communication. This was our working definition for “quality” Web sites. Other elements of quality, such as reading level and comprehensiveness may vary depending on the user and the user’s needs at a given time.

This document reviews the key, current literature on factors influencing the results of health searches. Each section highlights research and development recommendations generated by URAC’s expert group. The final section presents an action agenda that could be implemented by various interested organizations to improve the results of searches for health information. This paper is not an exhaustive review of research on online health search methods and issues. Rather, it highlights key issues from the literature and the stakeholder discussions that affect the results of online searches. The project was funded by a grant from The Robert Wood Johnson Foundation with additional support from the Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services.

2.3 A Framework for Thinking About Search Results

The process by which consumers seek health information online involves several stages, as illustrated below. The illustration is a simplified version of actual health search processes, which may vary from one consumer to the next. For example, some consumers may skip stages 2 through 5 and go directly to a trusted health site. In many cases, a consumer who is dissatisfied with the results at stage 5 may return to stage 2 or 3 and re-start the search process. However, this simplified model provides a framework for contemplating the online search process.

Each stage provides opportunities for improving the search process. For example, consumer education and awareness might improve steps 2, 4, and 5. Stage 3 offers opportunities for improvement through technological interventions. This project places some emphasis on the search engines’ role in processing queries as an efficiency strategy:

- There are fewer search engines than consumers, so there is a greater relative impact when a single entity makes a change at this stage.
- As specialized companies, search engines have the capacity to consider and implement complex selection or search criteria. Individual consumers are less likely to do so.
- Stage 3 is an automated process – once changes are written into search algorithms, these changes will apply to all consumers.
- Any change that a search engine makes may yield immediate improvements for search results for many consumers.

### Variables affecting results:

**Consumer has a health question or issue, and decides to seek information online**

- Internet access
- Literacy
- Language

**Consumer chooses a search engine and types in a search term.**

- Search behavior
- Assessments of credibility

**Search engine processes search and lists search results.**

- Type of search engine
- Search algorithm
- Ranking algorithm
- Paid listings

**Consumer chooses sites from search results.**

- Positioning of results
- Consumer quality evaluation
- Expert evaluation of quality

**Consumer reviews website information.**

- Actual quality/accuracy of information
- Relevance to consumer needs
- Ability to comprehend
An April, 2003 report from the Pew Internet & American Life report provided a useful overview of the U.S. Internet consumer population. The study suggests that Internet access has grown across-the-board, but demographic gaps remain. A variety of factors continue to separate Internet users from non-users. On the demographic side they found:

- Younger Americans use the Internet more than older Americans.
- Well-to-do Americans use the Internet more than less well-off Americans and the employed are far more connected than the unemployed.
- White Americans use the Internet more than African-Americans and Hispanics.
- Well-educated Americans use the Internet more than those who only completed high school.
- Suburban and urban residents use the Internet more than rural residents.

Pew also noted that consumers often overestimate their knowledge of their internet and their ability to locate information. A 2002 analysis by Houston, et. al. using Pew data found that chronically ill Internet users were often relatively new to the Internet, and that they were more likely than those in good health to discuss findings with their physicians. They noted a need to educate patients about searching for health information online and for tools to help them identify high quality information.

Pew found that about one-third of health seekers who find relevant information online bring it to their doctor. A study of physician views on online information found that physicians increasingly encounter patients who have conducted health searches. Many physicians reported having changed treatment protocols as a result of consumer requests. While most physicians indicate that patients have found accurate information, many believe that having to respond to information decreases efficiency, and challenges their authority, and that information may be inaccurate. The study concluded that quality of information on the Internet is critical, as it does influence both patient requests and physician treatment choices. Some health care organizations have embraced use of therapeutic prescriptions for patients to visit specific health Web sites as a treatment modality and a method to steer patients to the most credible Web sites for their conditions.
Comprehension, Literacy and Access Issues: Health information seekers often must have a fairly precise understanding of what information they are looking for in order to find the results they want. English is the dominant language of the Internet. As such, non-English speakers face additional challenges finding and reviewing information. One study on accessibility of the Internet for people with disabilities found that there are significant access barriers, but that governmental and educational health information web sites were more accessible than other categories, such as web portals and community sites.13

Use of specific terms, even those considered to be synonyms, has a significant impact on search results, particularly in directory searches. Research on consumer health search behavior shows that laypeople often enter popular/lay terminology for the concept, illness, or subject of interest, when they do not know a precise clinical term.14 Often, such Web search efforts lead to unrelated or misleading information for the less-fluent health consumer. Berland, et. al. concluded that accessing health information using search engines and simple search terms was not efficient, since high reading levels are required to comprehend Web-based health information.15 Also, the relevance of information located was often of limited value, which may have been due to terminology used in the original search phrase. Other studies have demonstrated that large knowledge gaps exist between lay and clinical terms, especially for the less educated.16

Consumer Search Strategies: Several studies have investigated behaviors that consumers exhibit to retrieve and assess the quality of health information on the Internet. Eysenbach and Köhler, examining Web searchers in Germany, found that although search technique was often sub-optimal, Internet users successfully found specified health information in an average of 5 minutes 42 seconds per question.17 One search optimization firm, iProspect, reports that users generally use the same search engine for all types of search requests. Users look at up to three pages of search results to determine relevance, and abandon a search if they do not find appropriate results in the first three pages. Users usually modify their query after abandoning an initial search, and may at that point change search engines.18 Information about consumer search strategies suggests that general purpose search engines have a business rationale for ensuring that health searchers locate what they want, since they may otherwise lose that traffic to another search engine.

How Consumers Evaluate Web Sites

Website Credibility: According to Manhattan Research, 51% of consumers agree or strongly agree that it is difficult to separate online health information that is credible from that which is not trustworthy. Eysenbach found that consumers assessing the credibility of a Website primarily looked for the source, a professional design, a scientific or official touch, language, and ease of use. Study participants never checked any "about us" sections of Websites, disclaimers, or disclosure statements. Very few participants noticed and remembered which Websites they had retrieved information from.19

Experts and consumers use different criteria for evaluating quality of Web sites. A Consumer WebWatch study of consumers reported similar findings to Eysenbach: once people get to a site, they do not use rigorous criteria to assess the site’s credibility. For example, they almost never referred to a site’s privacy policy. The average consumer paid far more attention to the superficial aspects of a site, such as visual cues, than to its content. Nearly half of all consumers (or 46.1%) in the CWW study assessed the credibility of sites based in part on the appeal of the overall visual design of a site, including layout, typography, font size and color schemes. In comparison, a parallel study revealed that health and finance experts were far less concerned about the surface aspects of these industry-specific types of sites and more concerned about the breadth, depth, and quality of a site’s information.20
3.4 Implications and Recommendations for Future Research

The findings from this section suggest that there is great variation in how consumers seek information via the Internet, and in how successful they are in searching for health information. Since there is significant consumer-level variation in how consumers search for health information, search algorithms that support variation and still return expected results will meet consumer needs most effectively. The literature suggests a need for strategies to support consumers who are looking for complex health information, particularly those who are not familiar with the Internet or for whom disability, literacy and English skills are a barrier.

Additional research is needed on information needs of different consumer segments and how to effectively educate differing consumer segments to improve the results of their health searches. Further, given the wide discrepancy in how consumers and experts evaluate credibility of Web sites, and a body of literature suggesting that there are problems with completeness and accuracy of Web site content, additional research is needed on how to efficiently validate the quality of Web sites and communicate this information to consumers.

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Additional research is needed on how to efficiently validate the quality of Web sites and communicate this information to consumers. URAC’s stakeholder groups recommended a number of key research topics that would help to illuminate consumer behavior. This information would drive content management and site construction techniques and technologies in health Web sites, search engines and educational approaches that could improve the results for consumers. Research priorities include:

- Conduct audience segmentation research to identify search needs and capabilities of demographically different types of searchers and searchers with differing health needs. Segmentation can drive education and outreach initiatives.
- Conduct research on how consumers use health terms and the impact of using specific terminology. How do people search for health topics? How does the search term and search starting point influence the end results?
- Identify with greater specificity which information consumers are actually reading and responding to on Web sites. Develop strategies to better understand what consumers really want from health information, and which elements of information drive behavior change. This will help identify “markers” to guide consumers and search engine information retrieval.
- Examine how people define a successful search experience. How is success defined both for the search process itself, and for retrieval of content? Research could be designed to better understand the cognitive processing that goes into a health search and to correlate satisfaction with the quality of search results.
- Conduct more research on search strategy. For example, searches starting at a health plan site might take a very different course than those beginning with a search site like Google. This information will help to prioritize outreach to different types of search developers and design support systems to facilitate consumer searches.
- Conduct research on differences between US and international searches, particularly in terms of how different groups search and how they assess credibility of health information on the Web.
- Conduct more in depth research on content factors influencing physicians’ perceptions of quality of Web based information, the effect of physician recommendations to patients about using the Web, and physician responses to patient queries about Internet information.
The structure of Web sites influences how information can be retrieved from the site by a search engine, as well as the usability of the site for consumers. The coding and structure of Web sites can facilitate retrieval by search engines, or it can pose a barrier to information retrieval. Coded information on Web sites provides additional information to search engines. Coded information is processed through the search engine algorithm, and determines whether and how the site is ranked in search returns. Unfortunately, the same tags and codes that can be used to highlight information on a legitimate Web site may also be used by "spoofers" who try to lure any traffic onto the site.

In general, Web sites can support retrieval of information on their pages by using metatags and keywords to guide search crawlers to important content. Metatags provide a means for relaying information directly to the search engine. The keyword "META" tag, embedded within the Web page formatting, is the defining code through which the search engine is directed to the exact keywords that are targeted by a specific site. Keywords are recognized indicators of specific services or products. Keywords can be used to increase specificity of searches and help Web sites to attract "qualified" traffic. One strategy for enhancing search rankings of "quality" Web sites is to code certain types of information for consistent retrieval by the search engine.

Some Web site features make it more difficult for search engines to retrieve and process information. For example, Flash, dynamic pages and page frames often obscures code or content from the search engine that might be needed to properly index a Website. Dynamic pages are created when a user visits the Website. This process allows a given Web site to integrate databases or run sophisticated programs but includes the risk of viewable pages not being generated correctly when an automated information retrieval program, or "search bot", visits the site. Other site limiters include content attached in Adobe PDF files, content in sites that require log in, and pages not linked from another site. Site developers could enhance retrieval of their information by "optimizing" their sites for indexing by a search agent.

A few studies have sought to establish a methodological framework on how quality on the Web is evaluated in field settings or actual practice environments. Eysenbach, et.al. found that there are wide-ranging differences in studies of the quality of health Web sites. There are significant variations in study methods and rigor, quality criteria, study population, and topic chosen. Operational definitions of quality criteria are likewise often inconsistent. As a result, the conclusions on quality of health-related Web sites vary widely. Eysenbach found that the most frequently used quality criteria include accuracy, completeness, readability, design, disclosures, and references provided. Largely unknown, however, is the degree to which search engines incorporate quality criteria in their search algorithms.

Simple, consumer-friendly indicators of quality are lacking on health Web sites. Griffiths and Christensen evaluated the quality of Web-based information on treatment of depression to identify potential indicators of content quality, and to establish whether accountability criteria are indicators of quality. They found that although the sites examined contained useful information, their overall quality was poor. Sites typically did not cite scientific evidence in support of their conclusions.

One topic of great relevance is the correlation between popularity of a health Web site and quality of content. In a study to determine the characteristics of popular breast cancer-related Websites and related quality, Meric, et.al. found that more popular sites (according to Google rank) were more likely than less popular ones to contain information on ongoing clinical trials, results of trials, and opportunities for psychosocial adjustment.
These characteristics were also associated with higher number of links, as reported by Google and AltaVista. More popular sites by number of linking sites were also more likely to provide updates on other breast cancer research, information on legislation and advocacy, and a message board service. Measures of quality such as display of authorship, attribution or references, currency of information, and disclosure did not differ between groups. In similar findings, Kunst, et al. found that while there is a correlation between credibility features: source of information, currency of information, and description of evidence hierarchy, on Web sites and accuracy of information, the association is relatively weak.

In similar findings, Kunst, et al. found that while there is a correlation between credibility features: source of information, currency of information, and description of evidence hierarchy, on Web sites and accuracy of information, the association is relatively weak. These findings suggest that additional research is needed to identify indicators of content quality, and to correlate consumer preferences to quality indicators. Sites that include content correlated with popularity may best meet the public’s desire for health information. Current search algorithms may not be in agreement with quality clinical indicators and performance measures currently used throughout the healthcare industry.

**4.3 Tools for Evaluating Web Sites**

Many tools and criteria sets have been developed to assist site developers in producing quality Web sites, and to support users in evaluating sites. As noted, consumers and experts use different criteria for evaluating the usability and quality of Web site information. To date, there is no clear evidence that validates one set of criteria over another. This creates challenges in developing search algorithms based on indicators of content quality. As this section describes, a number of efforts are under way to encourage health Web sites to adopt criteria developed by experts as indicators of quality.

**Codes of Conduct:** A wide range of tools have been developed to assist site developers to produce good quality sites and for consumers to assess the quality of sites. Ratings instruments include codes of conduct, quality labels, user guides, filters, and third party certification. Several studies have showed that consumers do not routinely seek out information on certifications or adherence to voluntary codes. No research has been done on the effect of compliance to a code of conduct on the Web site, although most standards require sites to implement privacy protections and disclosure of site information as consumer protections. A number of organizations have developed quality criteria for health related Web sites, some with verification and some completely voluntary. Voluntary, self-certifying standards have been developed by the eHealth Code of Ethics of the Internet Health Coalition, (www.ihealthcoalition.org/ethics/ethics.html), the American Medical Association (www.ama-assn.org/about/guidelines), and the Health On the Net (HON) Foundation (www.hon.ch). HON has produced the oldest and perhaps best known quality labeling system (currently used by more than 3000 Web sites). URAC has developed a health Web site accreditation program (www.urac.org) that involves independent verification of compliance with its standards. URAC accreditation includes review of the Web site by an external auditor and has been applied to more than forty Web sites.

**Web Site Rating Instruments:** Gagliardi and Jadad have conducted two evaluations of Web site rating tools, published in 1998 and 2002 respectively. They concluded that ratings instruments tend to proliferate and disappear, and that few have been validated for direct correlation between standards and quality. Their 1998 study identified 47 rating instruments, with fourteen providing a description of the criteria used to produce the ratings. Five of these provided instructions for their use. None of the instruments identified provided information on the inter-observer reliability and construct validity of the measurements. Their 2002 comprehensive assessment of 51 new (2002) instruments found that 11 were not functional, 35 were available but provided no information, and five provided information but were not validated. Many different rating instruments can be found on health Web sites. Few provide details on how they were developed, or provided instructions for use, inter-observer reliability and construct validity of the measurements.
Kim et al. reviewed published criteria for evaluating health-related information on the Web, and identified areas of criteria-based consensus. They identified 29 published rating tools and journal articles that had explicit criteria for assessing health related Web sites. The most frequently cited criteria were those dealing with content, design and aesthetics of site, disclosure of authors, sponsors or developers, currency of information (includes frequency of update, freshness, maintenance of site), authority of source, ease of use, and accessibility and availability. Their findings suggested that while many authors agree on key criteria for evaluating health related Web sites, development of more explicit consensus criteria is needed to support the needs of the general public.

**User Defined Ratings:** User guidance systems are being promoted more frequently to enable users to check if a site and its contents comply with certain standards. The tools allow consumers e.g. web site users to assess Web site credibility by responding to a series of questions. Tools may be specific, general, or targeted at particular categories of users. User guidance systems such as DISCERN (www.discern.org.uk) provide brief questionnaires for users to validate information on treatment choices. NETSCORING likewise gives guidance on all health-related information (www.chu-rouen.fr/dsii/publi/critqualv2.html). QUICK (www.quick.org.uk) provides children with a step by step guide to assessing health-related information on the Internet. Other organizations such as the National Library of Medicine, which operates MEDLINEplus, and the Medical Library Association, have developed guidelines and tips for consumers to evaluate health Web site content.

**Gateways:** Gateways are an approach to organizing access to the Internet through selection of resources based on quality and relevance of information to a particular audience. Gateways employ filters, either electronic or human, to accept or reject types of sites of information based on preset criteria. Internet resources are reviewed, classified, and stored with descriptive information. Within the gateway, this process improves the recall and precision of Internet searches for a particular group of consumers. The O M N I Project, a gateway aimed at students, researchers, academics, and practitioners in the health and medical sciences is being tested as a standardized gateway to evaluated quality resources in health and medicine (see www.biome.ac.uk/guidelines/eval/factors).

Another gateway type approach is to use domain name extensions to signify trusted content of participating sites. For example, the World Health Organization is considering the feasibility of requesting a “dot health (.health)” extension for a pre-selected set of trusted Web sites. These new internet domain names may be introduced in order to differentiate sites and to improve retrieval of information. In informal proposals describing the .health domain name, the extension would be reserved for health information, services and organizations under a framework promoting minimum standards of conduct. Oversight of web sites would be delegated to independent verifying organizations. The .health domain would establish a global, easily recognized label for health related web site and encourage adoption of voluntary standards and development of quality web sites. The advantage to sites for adhering to standards of content quality would be more ready identification of sites by search engines as a result of the .health domain name.

In the U.S., www.healthfinder.gov, is a widely used gateway to selected consumer health and human services information resources provided by U.S. government agencies and other organizations serving the public interest. The healthfinder®Web site provides basic information on topics and directs users to other primary information sources. Resources are selected primarily from U.S. government agencies, national voluntary, nonprofit, and professional organizations serving the public interest, universities, other educational institutions, and libraries, state and local government agencies offering information services beyond their geographic boundaries, and organizations partnering with government agencies. A limited number of commercially based resources are included in healthfinder®, such as online journals, news Web sites, and free information services not available from any government entity.

"Gateways are an approach to organizing access to the Internet through selection of resources based on quality and relevance of information to a particular audience."
4.4 Implications and Recommendations for a Research Agenda

The findings from this section suggest the need for tools to enhance recognition of quality Web sites by consumers and search engines. Such tools may be implemented by Web sites themselves, for example through increasingly sophisticated coding to highlight quality indicators. These tools may also be directed towards consumers, to direct them more effectively to relevant, high quality information. In addition, since there are currently multiple tools for evaluating quality of Web sites, future research could be undertaken to validate the effectiveness of these tools.

As noted, gateways filter information to increase its relevance to consumers and provide expert assessment regarding validity of sources. It may also be useful to develop more sophisticated search models for providing useful and relevant information to consumers via “customization” approaches. Such approaches could potentially be embedded in search algorithms. URAC’s stakeholder group identified a number of research priorities relating to the quality of Web sites that could be the beginning of a national research agenda. These include:

- Validate the link between quality criteria embedded in seals, logos, and standards and content quality, as well as the impact of such seals on both consumer behavior and Web site behavior.
- Research the tradeoffs in traffic volume and consumer satisfaction for health Web sites in trying to address multiple dimensions of quality. Dimensions may include accuracy, comprehensiveness, ease of navigation and reading level, as well as other factors.
- Conduct periodic studies on quality of content on Web sites to monitor changes since the seminal work of the RAND Web site quality study.
- Evaluate the quality and performance of interactive eHealth tools in influencing consumer decisions based on Internet health information.
- Evaluate content quality of Web sites reflecting various sponsors, e.g. .gov, .edu, .com, and .org to determine if generalizations can be made regarding comprehensiveness, accuracy, credibility or other characteristics.
- Continue efforts to validate rating/ranking systems for health Web sites and search engine results. For example, Consumers’ Union is developing a “Consumer Report” model for health Web sites.

In addition, more research is needed on the impact of Internet-based health information on outcomes. The benefits and risks of health information, both from a health outcome and system outcome (quality, cost), are poorly understood. Research priorities may include:

- Demonstrate the link (if any) between increased access to health information and outcomes: utilization, behavior change, knowledge, disease reduction, or other measures.
- Compare performance of health search engines by conducting trial health searches for selected diseases. Use validated quality criteria (accuracy/credibility) to evaluate sites that top search lists produced by various search engines to rank health search results.
- Examine the effect of the Internet in reducing the time from symptom to diagnosis, particularly for rare diseases, which may currently take years to diagnose.
- Research the link between health information, health seeking behavior and health outcomes.
- Examine treatment compliance for Internet information users versus non users.
- Study indicators in a chronically ill population with Internet intervention versus those without.
- Research the effect of the Web on health care utilization. Are specific types of content more likely to increase or decrease utilization?
Search engines play a critical role in indexing and locating mass amounts of information. Recognizing the different capabilities of searchers, many organizations are developing either electronic or human-mediated techniques for reviewing information and making a pre-selected set of information available to consumers. These mediated strategies work in tandem with Internet-wide searches that identify the universe of retrievable Web sites for a specific topic. This section addresses first the automated search processes, and then notes some of the tools being used to focus and narrow searches for consumers. One challenge to search engines and human mediators is making access to personalized information as effortless as possible, as consumers rarely use the advanced search features even currently available to them.\textsuperscript{3,34}

\section*{5.0 \textbf{SEARCH ENGINES AS MEDIATORS OF HEALTH INFORMATION}}

Search engines and Web directories play a central role in facilitating access to health information. Web directories are organized Web site listings put together by human reviewers. Search engine listings are put together by automated systems and lack a navigable structure. Directories usually concentrate on indexing Web sites, while search engines typically index individual Web pages. The user of a search engine enters keywords and returns a list of pages that contain those words. The user of a directory might not use keywords at all but can browse the topical index for what interests him or her, such as Health > Diseases > Physicians > By Specialty > Cardiovascular > Angina. With few exceptions, consumer searches for keywords will result in a valid match only if the keyword appears in the Web site's description. Hybrid models of search engines and directories have developed over time, as search engines have incorporated directory features to assist with issues such as categorization and site quality.

\textbf{Search Engine Indexing and Retrieval Methods:} Virtually all commercial search engines rely on large powerful databases which utilize automated search agents called robots (“bots”), crawlers or spiders. These search agents crawl the Web continuously to index information on Web sites. Crawlers capture meta data, page titles and textual content, and add them to the search engine’s index or main database. When delivering final search results to a user, the search engine’s algorithm compares indexed data to the user term to generate a match. In the past, the search engine market was dominated by such crawler-based search engines. Search engine algorithms are quite complex and scientific. As noted, they make frequent use of complementary directories aimed at optimizing and positioning Web sites in the right categories. While search performance can be quantified by experimental methods, actual algorithms are closely guarded as proprietary corporate information.

Most commercial search engines employ a similar strategy for indexing. One of the most important indexing factors is content, based on recognizable keyword descriptions. Some search engines use keyword location, frequency, phrasing, and density as indexing and ranking factors. The prevalence and type of links associated with a Web site is also a commonly used indexing parameter. The number of pages that have links to a site can influence its ranking in most search engines. Frequently used indexing factors include descriptive or specific Title Tags, Meta Tags, ALT Tags, Link Tags, specialized URL names, and timeliness of information. One limitation of electronic indexing is the vulnerability of search engines to “spoofers.” Spoofers create codes not related to actual content, to fool the search engine into sending traffic to the site. It will be a challenge to design codes or tags indicating health quality that cannot be spoofed by non-qualified sites.
To process a search request, the search engine matches the user’s terminology with an existing database of Web site information. Search engine databases include only Web sites that have been registered with or indexed by the search engine – hence the importance of Web site developers making their sites accessible to automated agents, or becoming known to directory developers.

**Ranking and Ratings:** Ranking of sites in the final display of search results is of great importance to Web sites, users, and search engines as ranking effectively drives the likelihood of particular sites being recognized and visited. A poorly designed or executed search may produce an unwieldy list of likely Web sites, in effect making it likely that some important results could be hard to identify among large resulting lists.35,36 As noted above, research indicates that consumers rarely look at more than three pages of results, making it critical for the best results to be displayed in the top listings. Searches that are too narrowly drawn may omit important sites.

Paid preference and placement within search engines plays a decisive role in what sites are retrieved in a given search.37 A study by CWW demonstrated that consumers experience considerable confusion about paid listings, and may not distinguish them from other returned listings. The Federal Trade Commission has also expressed concern about how paid placement is disclosed to consumers, and has warned search engines to clearly distinguish advertising from search returns. Search engines may operate their own paid placement programs or obtain search results from third parties, who in turn operate paid placement programs. Currently most search engine companies segregate paid ranking results by placing them above the non-paid results or prominently elsewhere. Many of these sites use terms such as “Sponsored Links” or “Sponsored Search Listings” to denote payment for rankings. In some cases, these sites display more than one set of paid placement listings, and these additional listings are labeled using terms such as “Recommended Sites,” “Featured Listings,” “Premier Listings,” or “Search Partners.” Other sites use much more ambiguous terms such as “Products and Services,” “News,” “Resources,” “Featured Listings,” “Partner Search Results,” or “Spotlight,” or no labels at all.

5.2 Evaluating Search Results

**Search Engine Performance Assessment:** Current metrics for evaluating search engines relate to their business performance, not necessarily the content relevance or quality of the sites returned by a search. Performance metrics now used by search engines include initial page retrieval capacity and the ability to revisit Web sites to update information. In addition, the currency of information, as demonstrated by elimination of non-working links to Web sites, is a performance metric. For proprietary business reasons, most commercial search engines do not publicly disclose information about their algorithms.39

For health queries, key information that would facilitate evaluation and improvement of health web site retrieval includes:

- Identification of specific algorithms that determine how the search engine decides the order in which it returns information requested.
- The effect of paid placement practices.
- Identification of programmed processes that detail how that specific search engine looks for information, and how often their information is updated.
- Objective evaluations of authority, appropriateness, and validity of information located.
- Indicators of the type and degree of “quality filtering” employed to minimize retrieval of information that is clearly inaccurate or bogus.

5.3 Techniques for Mediating Search Results

**Search Filters/Blocks:** Recent studies have shown that health information may be intentionally or unintentionally blocked from users. Many search engines offer “filters,” that allow users to exclude unwanted search results (typically pornographic sites). Users, including libraries, can also install blocking software to prevent unauthorized use. Because pornography-blocking software and filters cannot perfectly discriminate between porno-
graphic and non-pornographic Web sites, such products may block access to legitimate health information sites, particularly those related to sexuality.40

Niche Search: Niche search engines provide for an industry-specific or content-delimited search result, increasing the chances of efficiently finding information. A niche search engine can zero in on specific topics and different levels, such as healthcare, mental health, or a specific mental disorder. Niche search engines cater to a specialized community or sub-population. As such, they can be designed to find and index documents about e-health, medical treatment, or related resources. In a niche search, the search engine parameters are pre-defined to include the Web sites of specified healthcare entities to retrieve and catalog a variety of information resources.

“Mediated searches may be as simple as having a librarian assist with a search, or they may be based on much more complex algorithms.”

Complex algorithms. Participants in the URAC/CWW stakeholder group noted that medical and general librarians play an important role in helping large segments of the population retrieve online information and learn effective search strategies.

A prototype example of a more complete mediated search which may applicable in healthcare settings is The Virtual Reference Desk (VRD), a project dedicated to the advancement of human-mediated digital reference services. VRD is sponsored by the U.S. Department of Education. This project provides online Digital reference (AskA) services. AskA is a network of volunteer information professionals that ensure user questions are addressed by the most appropriate experts. Digital reference services use the Internet to connect people with people who can answer questions and support the development of skills. While it has yet to be evaluated, the VRD model may provide a framework that is adaptable to health consumer information delivery and education. Another promising mediated search strategy is the use of agent-based mediated searches.

NASA is testing the ILIAD system as a prototype. ILIAD is part of a national effort to provide communications technology and networked information to the education community and Internet users at large. ILIAD provides intelligent, selective access to Internet information through two avenues; a simple low-cost email interface, and a Web-based form. ILIAD is an electronic information assistant that retrieves and processes information from the Internet without extensive user-based search refinement.41

5.4 Implications and Recommendations for a “Search” Research Agenda

Search engines are increasingly important as a tool for locating and organizing information from the vast Internet resource. The volume of information on the Web is so significant that consumers may need different types of mediators such as search engines or librarians to help manage the volume of information. Human mediation or review is also helpful to counteract electronic spoofing.

Consumers are often unaware of the limitations of their search strategies, or aversive to using either electronic or human search support systems. It may be possible to develop search technology to intuit consumer needs more effectively and help to steer them to quality results. The findings from this section suggest that more information about search algorithms and how “quality” factors are identified in the algorithms, specifically for health, would be of value.

A number of new technologies could be used to “mark” quality content or assist search engines in “learning” as they search. Search engines are also developing technology to search for synonyms, which may enhance health searches conducted by laypersons. It may also be helpful for search engines to develop methods to distinguish health-related searches from other types of searches, rather than using a simple word match. These technologies may ultimately be more effective than electronic filtering, requiring consumers to apply filters, or modifying their search strategies.
With technology advances, search engines may be able to identify quality proxies that could improve page rankings of high-quality Web sites. Search engines could, for example, give higher ranking to “official sites” for diseases. They could also piggyback onto credibility assessments provided by groups such as healthfinder.gov, or give higher ranking to sites listed in directories from trusted independent sources. Most search technologies have yet to be tested and evaluated. Ultimately, adoption of technological solutions depends on the ability of researchers to understand the relationship between electronic proxies for quality and actual quality content.

Additional research is needed to assess the effect of technology, differences in search engines and the relationship of search results to consumer needs and actions. Research priorities include:

- Identify retrieval characteristics that could improve dissemination of the most current health information. Conduct studies on the amount of time it takes for search engines to replace information that is discredited or outdated.
- Research the relative effect of each component of a search algorithm (word frequency and placement, links, etc) for finding health information.
- Research technological strategies for identifying the intent of searchers and “learning” from repeated searches in order to better meet searcher needs and return more appropriate results.
- Evaluate the differences in traffic and links between high and low “quality” sites as a method for testing the search engines’ theory that the frequency of links is an indicator of value/quality.
- Replicate and extend the findings from seminal research studies, such as the one conducted by the RAND organization to evaluate search engine performance for standardized health queries for both high and low prevalence clinical conditions.
The URAC and CWW expert panels discussed consumer, Web site, and search engine factors that influence the outcomes of health searches. In the course of discussion, they developed a number of recommendations for future research and development. Their recommendations fell into several categories: needs for health services research, consumer and provider education, technological improvements, and development of tools and information to improve the results of health searches. For some recommendations, the evidence base for implementation is strong; for others, not.

Implementation of some recommendations will be enhanced by creation of a national research agenda for health information and targeted funding to study and improve consumers’ ability to locate and retrieve quality health information on the Internet. Other recommendations could be embraced at any time by researchers, educators or technology organizations as a business need becomes increasingly evident.

The initial steps of a research and development agenda are highlighted below as recommendations from the URAC/CWW stakeholder groups:

**Developing a National Research Agenda and Supporting Methodologies**

- Organizations with an interest in improving health literacy should continue to collaborate to improve access to quality Web-based health information, and to recognize the importance of health searches in accessing health information. Federal agencies, national health organizations and Web content developers clearly have an interest in this area.
- Collaborators should convene a leadership summit on health search literacy to discuss feasibility and implementation of many of the recommendations in this paper.
- Funders, including foundations and the US Department of Health and Human Services should set up a comprehensive long term research agenda for improving Internet health information. HHS has already established national goals for health communications that can serve as the foundation for the agenda and has published an action plan on health Web site quality. The California Health and Human Services Foundation has also identified a number of recommendations for improving Internet-based health information that should be part of the agenda.
- Develop methodologies to test the effectiveness of online information on consumer action. The methods should be appropriate to produce statistically valid findings for specific segments of the population. We may also need to employ new technology to conduct the research, for example, on search behavior.

**Stakeholder Action Agenda**

Stakeholder actions are activities that could be developed by organizations and advocacy groups using information and tools that are currently available. Some of the recommendations developed by the group are consistent with current funding and the agendas of specific stakeholder groups. Other recommendations will require development of new partnerships and collaborations between consumer, education, health, and technology organizations. Some recommendations may need further evaluation or research to enhance the evidence in favor of the intervention prior to implementation.

**Consumer Directed Tools**

- Encourage credible health groups to create tools to support consumer health information needs. For example health organizations could create folders of preset Internet bookmarks that could be saved onto consumers’ browsers for frequent use.

*As described in the introduction, all participants have reviewed the recommendations and have had the opportunity to comment on them. We did not seek endorsement or consensus—therefore not all participants approved of all recommendations.*
Identify and develop consensus around a prototype brochure or document on health search strategies. This document could be printed with the distributors’ logo and distributed by health groups, employers, providers and others to educate consumers on effective search and evaluation strategies.

Develop publicly available, interactive, validated search strategy content pages that could be branded by and uploaded to Web sites and used in consumer education initiatives.

Develop models for offering health search education at teachable moments and in diverse consumer resources. Examples could be search tips printed on the back of physician prescription forms, in member enrollment information, and new parent packs. Search strategy information could be added as links to HMO and hospital portals.

Promote dissemination of existing resources to assist consumers in evaluating health information on the Web more effectively. Examples of resources for consumers include MEDLINEPlus and the Medical Library Association’s search and evaluation resource. Dissemination efforts could include optimizing sites to facilitate their retrieval in the context of other consumer health searches.

Education Agenda

This series of recommendations could be implemented by education organizations, provider groups, and health services researchers.

D evelop tools and approaches to assist Internet users with special needs, based on consumer segmentation research.

“Develop tools and approaches to assist Internet users with special needs, based on consumer segmentation research.”

Develop tools and approaches to assist Internet users with special needs, based on consumer segmentation research. High priority consumer segments may include the disabled, low literacy, and non-English speaking groups. Examples of tools include offering human-mediated searches, incorporating reading level rankings as a quality factor in Web site evaluations, and identifying Web design factors that enable users to access the site.

Provider organizations should educate provider members on the value of offering online health information as part of a therapeutic encounter, and provide them with tools to assist and steer consumers to high quality sites. These groups should provide education for physicians on how to work with patients on Internet searching, perhaps using the search education brochure and Web pages described above.

Health organizations should educate health Web site developers on how to make information easier to find and how to meet the user needs of their intended audience. For example, health Web sites may be able to tailor their reading level and navigation features to promote access.

Education organizations, in collaboration with health organizations should develop a school-based or publicly available health search curriculum for those who would be amenable to it – for example, parents/grandparents who are not as Internet savvy. For younger consumers embed educational components in the search itself, for example, through pop up clarifiers or questions.

Technology Improvement Agenda

These recommendations could be implemented through technology innovations adopted by the search engines themselves, or through the development of “marker” technology embedded in health Web sites.

Search engines should continue to develop interactive features on search engines and sites to customize and personalize health searches. These could be visible to consumers (such as creating a demographic profile) or invisible, through search engines that “learn” consumer preferences for types of Web sites. Search engines could also develop capabilities to query searchers on their intent. The technology would have to be compatible with acceptable standards for ensuring the privacy of consumers.

Enable search engines to mediate selected health queries by offering additional relevant information. For example, search engines could offer relevant links for general health searches, such as the Food and Drug Administration Web site, for users who search for pharmaceutical drug names.

Develop technological markers or indicators that capture accuracy and comprehensiveness of health Web sites as performance elements that would enhance a site ranking in search results. Accreditation may be one such quality indicator.

Develop technology to indicate when information “supercedes” previous information. The “supercedes” function will push new guidelines up in search listings and archive outdated guidelines.
Search engines could collaborate with researchers on quality of health information to identify validated quality proxies to embed in search algorithms. This would serve to increase search return rankings of higher rated health Web sites. “Expert” raters might include medical specialty societies, accreditors, and the federal government. Other factors to consider to enhance search algorithms (particularly after additional validation work has been completed):

- Giving priority to links from selected ratings organizations such as medical specialty societies or federal agencies;
- Developing or using existing text markers, such as the words “prescribing information” in proximity to drug information;
- Increasing rank of domain names ending in .gov, .edu, or .org.

Search engines could develop technology similar to that used in commercial sites to direct consumers to health information, compatible with their actual search and viewing behavior. For example, develop a function to clarify and enhance health queries: “People who search for xx also often search for xyz.”

- Enhance personalized searches by building in the capacity for search engines to remember customer search strategies and what they are looking for, compatible with appropriate privacy protections.

**Expanding the Market for Quality**

Health care or provider organizations could develop a health equivalent of bizrare or ebay surveys that can be used by consumers to evaluate a Web site after using it. The ratings could be factored into search algorithms to drive traffic to higher rated sites.

Search engines, in partnership with funders or health care organizations could sponsor a competition for individuals or organizations to design an algorithm (and a business plan to support the algorithm) that returns the most credible health results. A panel of experts could determine which sites are most credible for selected health queries. Categories might include chronic disease, emerging disease, and conditions for which evidence is rapidly changing. The contest would reward entrants that create an algorithm that returns the most credible health sites.

**Conclusion**

The Internet has opened a vast library of information to consumers of health information and made that information more accessible than ever before. The volume of information and the variable quality of information has created new interpretive challenges. Now, one great challenge is helping consumers find the information they want that is also accurate, reliable, and presented in an accessible format. Searches for health information rely on a complex interplay of search algorithms, Web site content and coding, and consumer behaviors. The recommendations presented here address each of those factors with ideas for further research as well as more immediate recommendations for action. This agenda is a start at maximizing the potential of the Internet to deliver high-quality health information for diverse users.
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