

HealthAware: Lessons Learned in Developing a Consumer/Patient Information Portal for a Health Care System

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PROJECT DESCRIPTION

HealthAware is a Web-based information resource designed for consumers to provide health, wellness, and health care content. Unlike many consumer health sites, HealthAware seeks to “close the loop” when the need for care arises. This is achieved by providing locally developed content as well as more generic materials, interactive risk-assessment tools yielding recommendations for referral, and a resource locator that facilitates identifying a provider through a local health care provider network; requesting an appointment; and finding local educational opportunities, support groups, and other resources¹⁻³. Thus, HealthAware is intended to function as a consumer/patient portal for a health care enterprise.

As a prototype system with grant/contract support, HealthAware was able to provide only limited content coverage. Content development and organization focused on five medical domain areas: breast disease, cardiovascular disease, sports-related injuries, prenatal care, and substance abuse. We implemented the system at Brigham and Women's Hospital (BWH), with a pilot testbed user community at Boston College, including the faculty, staff, and students (hence, the particular mix of content areas).

To implement the system, a set of tools was developed. Editing tools were used to author and update content in module-specific database files. A distributed authoring/editing approach facilitated editorial review and approval analogous to publishing. Dynamic page generation from the databases enabled easy content update and ensured a consistent look and feel. The system was designed to enable both external content and locally developed materials to be incorporated, with appropriate disclaimers and acknowledgments.

Evaluation goals were to (1) understand consumers' information needs and usage patterns and (2) evaluate opportunities for improving the quality and appropriateness of referrals.

A user-centered design approach was adopted in developing content and methods for presentation and interaction for the five medical content domain

areas of focus for this project and for the risk-assessment tools and referral tools. Strategies used for content and site development included (1) requirements analysis for patient-specific educational materials (new and existing materials), (2) a design that included a blend of both generic content and local content with direct links to local resources, (3) usability testing of interface design and all interactive tools, and (4) questionnaires and interviews to assess the perceptions and attitudes regarding the implemented system.

We found that consumers put considerable emphasis on the quality of the medical content. On the basis of our literature review and preliminary interviews with consumers, it was apparent that although there is a plethora of health-related information on the Web, interviewees felt that content was often not available on specific topics of interest to them and recognized that quality was variable and unreliable⁴⁻⁷, with uncertain expertise of authors, outdated materials⁶, or questions of sponsorship.

Readability of some HealthAware health information content was deemed too difficult by test subjects. Content was rewritten at an eighth-grade literacy level, and medical terms were rewritten in plain English. Users had trouble connecting the word “heart” to “cardiovascular” and “clot” to “thromboembolic.” Another factor confounding the literacy issue may have been an emotional overlay (e.g., What does this mean for me?). Methods used to assess reading level included Flesch-Kincaid and McLaughlin SMOG, for which accuracy is reported to be within ± 1.5 grade levels.

LIMITATIONS

This study faced a number of challenges, owing in part to the need to establish a limited testbed setting in terms of study population and breadth and depth of content coverage. As a consequence, we were unable to sustain a critical mass of usage. Constraints in contract funding prevented procuring external content or significant local development of content. Due to the limited number of topics covered, the site could not be promoted as a comprehensive health and health care resource, only in the context of the specific

diseases and problems covered. Thus, the site was not the first source that a typical user would think of from which to seek answers to health questions, given the emergence during this period of large national health information Web sites. Continual promotion was needed to remind users of the availability of this resource for particular problems, which was difficult to sustain, and the interest of users in terms of repeat visits was difficult to hold.

For those patients who had subsequent health care visits or interactions with the health care system as a result of information or advice obtained from HealthAware, we wanted to follow up with them and their doctors to assess the perceived impact of the Web site on the subsequent encounter. To do this, we needed to be able to identify users who had health care system contact and whose entry into the system came from HealthAware. To develop a denominator, we tried requesting user identification and contact information with consent from all users, but this request, when made as a requirement for proceeding, dramatically reduced usage. Asking for it optionally resulted in almost no entries. Therefore, we abandoned the request for identification for all users and requested this information only when a specific referral request was made. According to the BWH teleservices department, the total number of online referrals increased over the study period. Because users were anonymous in their searching, we do not know what percentage of online referrals was generated through the HealthAware project.

SUCCESSSES

Our approach of tying the site to local health care resources appeared to have appeal, according to focus group and interviews we conducted. Furthermore, working with BWH's marketing department and care improvement committee, we found endorsement of the view that this mechanism was effective for referral into the health care system, in that it provided a new opportunity to develop a relationship with a patient. Once the relationship was developed, the site could function as a portal to a particular practice as well as to related health and health care information. This of course requires that the user identify the health care system as a source of health information, so it has been successful only to the extent that we have been able to set up a portal strategy.

A number of Web health content providers either are now marketing approaches influenced by or have adopted the HealthAware approach: offering health content for branding or cobranding by a

health care system and offering tools for integrating risk assessment and referral into the health care provider network. Examples are HealthGate, HealthVision, HealthCentral, drkoop.com, and healthyconnect.com

This project has resulted in adoption of a Web strategy and plan at BWH to make the kinds of capabilities developed in HealthAware available on a continuing basis, augmented by a corpus of external content. The strategy of creating a portal for the health care system or for particular practices, where content as well as interactive communication resources, risk assessments, and referral are provided—which was the basis for the HealthAware approach—is now broadly accepted by BWH. Plans are under way, led by BWH marketing personnel and with the support of a BWH Web committee, to implement this capability in conjunction with a commercial content provider. HealthAware-like capabilities are expected to be incorporated into the system.

BWH is also building a center for patient education (the Bretholtz Center) where consumers and patients can access health information and resources through computer stations with a HealthAware-like interface and interactive tools.

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