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Expanding Access to Consumer Health Information: A Multi-Institutional Collaboration

by

W. Bede Mitchell, Peter Sullivan, Mary Kate Pung, and Lisa Smith

Abstract: A partnership between an academic library, a public library system, and an area health education center meet a critical information need in a rural region of southeast Georgia.

The Problem: The Statesboro Regional Library System (SRLS) in southeast Georgia receives hundreds of inquiries per month from people who need reliable and understandable health information. The medical consumer is becoming increasingly concerned about healthcare costs, quality, access to medical care, and information on how to stay healthy. Patients are increasingly responsible for providing their own health education. The General Mills American Family Report: Family Health in an Era of Stress indicated that "Many times the consumer is unwilling or unable to get information from the direct source: the Health care Provider."¹ The healthcare consumer must be more informed, be wary of inept practitioners and hucksters, refuse to accept statistics appearing in the media on face value, select practitioners with great care, question diagnoses and treatments, and provide support to efforts to improve safety of medical products and services. An example of the confusion which healthcare consumers must live with is popular media information on vitamin E; once blessed as useful for almost everything, recent studies indicate it is no more

effective than a placebo. In an effort to cope with all these challenges the health care consumer resorts to friends, neighbors and libraries to answer many of these increasingly important questions.

As noted above, the growing cost of medical care is an important reason many consumers seek information from sources in addition to their primary care giver. Since 1970 the cost of medical care to the average citizen has risen 456 percent. Recent figures indicate the United States spends more than one billion dollars per day on medical care. Due in part to these increasing costs, the number of annual patient visits to doctors during the past twenty years has been dropping. Reduced access to physicians has required patients to learn more about their medical conditions and treatments on their own. Further, even when patients consult physicians they have little time to ask questions. Surveys taken as early as 1992 indicate that the average contact consumers had with his or her physician was 17.5 minutes.² Recent surveys show that physician-patient contact time is increasing slightly in length (one minute on average)³ but primary care providers must now cover many more topics with patients than they once did. Over one-half of the medically insured population of the Statesboro Regional Library (SRL) service area is enrolled in some form of managed care,

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which introduces another player to the process of making healthcare decisions – the HMO case manager. Thus in the era of HMOs and increased patient involvement in the delivery of their healthcare the need for accurate and timely consumer health information has never been greater.

¹ Rees, Alan M. Encyclopedia of Health Information Resources. 2nd edition. Detroit, Gale Research International, 1993. p.viii.

² Mechanic, David; McAlpine, Donna D.; Rosenthal, Marsha. "Are Patients' Office Visits with Physicians Getting Shorter?" New England Journal of Medicine, Vol. 344(3), 18 January 2001, pp. 198-204.

³ Mechanic, David. "How Should Hamsters Run? Some Observations About Sufficient Patient Time in Primary Care." BMJ. Vol. 323, 4 August 2001, p.266-8.

What are the best sources for consumers to seek the healthcare information they need? Rural healthcare facilities have been unable to keep up with both changing technology and the sheer volume of published materials which cover the main issues of consumer healthcare, such as signs, symptoms, causes, diagnosis, and treatment of diseases and medical conditions. The Statesboro Regional Library, its affiliates and the academic libraries of the community have attempted with some success to fill the need for consumer health information. But limited budgets make it as difficult for libraries to keep their healthcare reference collections up to date as it is for the healthcare facilities to do so. On the theory that no information is better than bad or outdated information on library shelves, the SRL and its affiliates discarded from their collections 6,000 outdated volumes.

With the growth of the Internet, it is not surprising that more and more people are seeking useful and reliable health information online. Two out of three Americans aged 15-24 say they used the Internet to search for health information, and one in four reports getting "a lot" of health information from the World

Wide Web. The only online activities they spend more time on are email and school research.⁴ In 1997, Dr. Tom Ferguson, author of *Health Online*, estimated that there were more than 25,000 health-related Web sites plus Usenet and chat forums devoted to health issues. The ease of access and volume of health-related information available on the Internet increases daily. The Internet is changing medicine for the better by allowing patients to better educate themselves. Approximately 41 million Americans used the Internet in search of consumer health information during the year 2000. In a September 5, 2001 interview on National Public Radio's TALK OF THE NATION, Dr. Ferguson reported that a Pew Internet and American Life Project survey had found 57 percent of all U.S. adults who use the Internet have used it to seek health information. However, the major issue and concern with health information on the Internet is credibility.

⁴ "Briefings: Gen Y Looks to Net for Health Info." NetConnect, Winter 2002. p.4.

The FDA has reported investigating Web sites that were created to sell worthless drugs and which gave advice to people that had no grounding in science or logic. Many people in highly stressful medical crises put themselves or their loved ones at risk when searching for medical information online. An Arizona physician and pharmacist emailed to the September 5 TALK OF THE NATION program that in her independent counseling practice she spent the majority of her time in damage control: "I explain the information that patients have acquired with respect to their medical conditions and why it is or is not accurate or relevant."

The Solution: In 2000 the director of the SRL, the dean of the library at Georgia Southern University, and the director of the Magnolia Coastlands Area Health

Education Center (MCAHEC) began exploring how the three organizations might collaborate to deliver quality healthcare information to consumers. Several issues were identified which, if addressed adequately, would improve consumer health information available to the citizens of the Statesboro Regional Library service area. These issues were:

- outdated information in library collections,
- the difficulty in identifying reliable sources of juried health information sites on the Internet,
- lack of access to the Internet for many residents in the southeast Georgia region, and
- insufficient training on the part of library staffs and consumers in seeking out quality consumer health information in various publication formats and on the Internet.

On February 6, 2001 the three organizations agreed to form CORAL (Coalition of Regional and Academic Libraries) and develop programs for meeting the region's consumer health information needs.

The Statesboro Regional Library System is a five-county southeast Georgia public library system serving a population of about 121,000. Statesboro is located about 45 miles from Savannah. A staff of more than forty includes seven professional librarians who provide direct services and consultant services to affiliated county libraries. The regional library director, the Business Services Department, and the Technical Services Department also have system-wide responsibilities. A Regional Library Board of Trustees governs the entire library system and is made up of two members from each local county library board.

Georgia Southern University, also located in Statesboro, is a constituent campus of the University

System of Georgia and is the largest and most comprehensive center of higher education in the southern half of Georgia. A residential campus of 14,200 students, Georgia Southern serves its mostly rural coastal region through outreach and research in economic development, education, cultural opportunities, rural health, and environmental interests. The Zach S. Henderson Library makes its information resources and services available to the general public as well as Georgia Southern's students, faculty and staff.

The Magnolia Coastlands Area Health Education Center (MCAHEC) serves 39 counties in southeast Georgia, 34 of which are classified as rural or non-MSAs (Metropolitan Statistical Areas). A recent needs assessment for the MCAHEC service area revealed a serious shortage of doctors, physician assistants, nurse practitioners, occupational therapists, and physical therapists. The coastal counties are experiencing heavy growth, which will increase demands on the health care workforce located in the easternmost communities. The AHEC challenge is to assist these communities in obtaining health resources and opportunities to improve the quality of life.

CORAL submitted a proposal for Library Services and Technology Act funds, with the stated intention of improving the access of consumers and professionals to quality healthcare information. To achieve this overall goal, CORAL set the following objectives:

- To select quality consumer healthcare books to add to member library collections.
- To provide the general public quality consumer health information online.
- To provide the necessary technology to link library users to quality Internet sites by establishing a CORAL Web site.
- To select the best consumer health sites on the Internet.

- To link the citizens of the SRL service area to the best possible consumer health Web sites.
- To develop a public relations package to support and advertise the CORAL Web page and consumer health information available in libraries.
- To develop teaching materials regarding reviewing and selecting quality consumer health information.
- To present a workshop to the professional staffs of all the libraries within the SRL.
- To present workshops for the general public on how to access and evaluate consumer healthcare information.
- To evaluate the quality and presentation of the workshops and materials created and used by CORAL.

The proposal received \$20,000 from Library Services and Technology Act (LSTA) funds administered through the Georgia Office of Public Library Services and local funds. CORAL set to work selecting books and videos for the physical library collections, and Internet sites to which consumers could link from CORAL's healthcare Web page, which was dubbed the CORAL Health Education Network (CORAL HEN). The Henderson Library agreed to host the HEN site on its server and provide maintenance support. The site was planned from the outset to be as simple as possible. First, a simple design would minimize the time spent by Henderson Library's Webmaster in designing and maintaining the site. Second, design simplicity was also important because it was expected that a large segment of the intended audience would not be very sophisticated Web users. Third, because many people in the region with Internet access do not have high-speed connections, an elaborate site design would take an unnecessary amount of time to download. With the need for

simplicity well established, Henderson Library participants were confident they could take on the site creation with only a modest addition to the Webmaster's student staff. A remaining concern was that of whether the demand for access to the site would be a discernible burden on the library's server.

The CORAL board of directors decided to move ahead without finding the resources to enhance the Henderson Library server. It seemed unlikely that demand would be very heavy at the outset, and if over time usage demonstrated the site was meeting a significant demand but slowing system performance then it was likely the server could be enhanced through grant funding. While CORAL HEN has only been publicly available since October 2001, to date the demand has not challenged the library server. The site may be visited at <<http://www2.gasou.edu/library/coralhen/>>

A subcommittee of librarians set about developing a selection policy for the Web sites to be included in CORAL HEN. The subcommittee began by incorporating standard criteria for evaluating information on the Web, including authority, accuracy, purpose, scope, and currency. Health information, however, requires more careful evaluation than these basic criteria. The final CORAL selection policy employs the following specific criteria:

1. The content of the site should be written primarily for consumers rather than healthcare professionals.
2. Sites with an editorial board responsible for site content are selected over those without a board, or those appearing to lack any form of peer-review of the content.
3. The purpose of the site must be clearly stated, including the intended audience.
4. The scope of any medical Web site is limited and will not include all information

relevant to the user, therefore a clear and concise disclaimer must be prominent on the page.

5. The site must be updated frequently, and the last update time should be clearly indicated.
6. Information provided must have contact information and credentials of the author(s).

In keeping with CORAL's own selection criteria, a disclaimer was included on the CORAL HEN home page. It states:

The general information offered in this Web site is not intended as a substitute for medical or other professional healthcare advice and treatment. While we have exercised care in providing information, including links to other sites, no guarantee can be made as to the accuracy, timeliness or applicability of any information contained in this Web site or any Web sites to which links are provided. This Web site does not contain information about all diseases or conditions. It may not contain all relevant information. Content provided in this Web site is only general health information, intended to facilitate communication between you and your healthcare provider. It is not intended for diagnosis and cannot provide diagnosis for any particular individual. It should not be used as a substitute for seeking professional medical advice, diagnosis, treatment or care. If you have any questions or concerns about your health, please contact your healthcare provider.

As the CORAL site development neared completion, a series of "sneak previews" were conducted for the local medical and academic communities. It was

essential that local physicians, nurses, and the faculty in Georgia Southern's College of Health and Professional Studies (CHPS) be apprised of the project before it was promoted to the public. The CORAL board of directors did not want medical professionals being asked about information obtained through a local resource with which they were unfamiliar, and the board did want the medical community and college faculty to have the opportunity of offering ideas and suggestions about the project and the consumer healthcare site. Brief presentations were given at CHPS department meetings, and a drop-by demonstration was held for local physicians and nurses at the East Georgia Regional Medical Center in Statesboro. These sneak previews were very well received and many useful suggestions and insights were obtained.

Meanwhile, the MCAHEC participants designed workshops for library personnel at Henderson Library and the SRL system libraries. Each workshop attendee was given a manual that included the workshop's objectives, a printout of the presenter's PowerPoint slides, a brochure on PubMed (a Web-based retrieval system developed by the National Center for Biotechnology at the National Library of Medicine), a "webliography" of all highlighted Web pages, and more. The workshop's outline:

- I. Introduction to Consumer Health Information
- II. Evaluating Consumer Health Information
- III. Types of Health Web Sites
- IV. Specific Consumer Health Information Web Sites
- V. Tools for Consumers (sources from National Library of Medicine and other sites)
- VI. Tools for Librarians (for ex., pathfinders for health information, evaluation resources, training materials, etc.)

Assessing CORAL'S Effectiveness:

The CORAL HEN partners believe the goals of the grant have been achieved.

- I. More than 900 consumer health books and videocassettes were purchased for use in the regional network of consisting of five public libraries. The Regional Library is now well on its way to being a net lender of consumer health materials through PINES.
- II. Two staff workshops were held, one for 49 regional library staff members and one for eight university librarians.
- III. Three consumer workshops were held, attended by 22 participants.
- IV. A consumer healthcare information site was established on the World Wide Web.
- V. A comprehensive public relations plan was launched to inform the general consumer about the services available.

The Future of CORAL: The next step in developing CORAL is to gather user feedback which will lead to improvements in current collections and services, as well as inform the board of directors about other consumer healthcare information needs which CORAL might address.

The CORAL HEN partners have already developed the following plans for expanding the project:

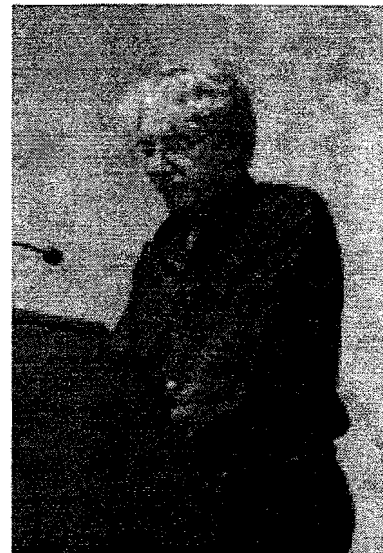
- Add low-literacy resource sites to the Web page.
- Purchase additional consumer health oriented library materials.
- Add an on-line survey of Web site users.
- Develop additional workshops addressing specific needs of targeted groups such as older adults, students, special interests,

consumers needing low-literacy services, resources, and church groups.

- Add a section to the Web page to highlight local consumer health events such as screenings, education sessions, or new services.

The success of this collaboration is due to the complementary strengths and resources that each of the partners brings to CORAL. It is a good example of how different kinds of institutions can serve their overlapping constituencies better by working together.

NEWS FLASH



The Athens-Clarke County Library celebrated the freedom to read with a Banned Books "Read Out" on Wednesday, September 25, 2002. Pictured above is Mike Mills from R.E.M. reading a passage from Slaughter House Five. Other community members who read a 15-minute passage from a banned or challenged book throughout the day include Library Director Kathryn Ames, Author Coleman Barks, Mayor-Elect Heidi Davison and UGA Athletic Director Vince Dooley.