

THE CHALLENGE OF PROVIDING CONSUMER HEALTH INFORMATION SERVICES IN PUBLIC LIBRARIES



AMERICAN ASSOCIATION FOR THE
ADVANCEMENT OF SCIENCE

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THE CHALLENGE *of* PROVIDING CONSUMER HEALTH INFORMATION SERVICES *in* PUBLIC LIBRARIES

INTRODUCTION

One of the biggest challenges today's librarians face is an insatiable consumer demand for health information.

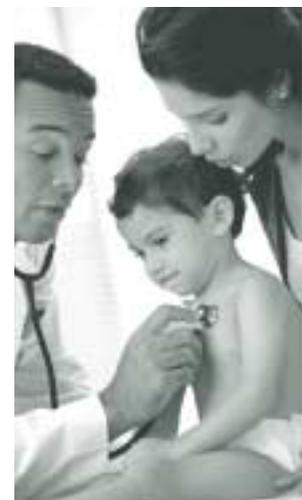
Personal health care management has become a big business. Consumers are bombarded with information on television and through other media sources that say it is possible to live longer and be healthier by taking better care of themselves. A plethora of health care information books, Web sites, television programs, magazines, CD-Roms, DVDs and videos explain how to improve health by eating smarter, exercising more frequently and improving management of treatments associated with chronic illnesses. Studies in medical journals suggesting new and often counter-intuitive approaches to health care are cited constantly on television news programs.

It's not surprising that Americans are hungry for health information. According to recent studies, the average doctor's office visit in this country lasts 12 minutes. With limited time to ask questions, the more patients

are informed about specific medical conditions affecting their health, the smarter the questions they will ask their doctors. And the place that many people go to find answers to their questions, and other health information is their local public library. In some communities, hospital and medical libraries also provide services to the public.



The role of the librarian has expanded to meet this need. Only a small percentage of America's 16,000 public libraries have the funding and resources necessary to establish and maintain the specialized consumer health information centers that some libraries or library systems have established. Yet all public libraries, whatever their size or resources, must attempt on a daily basis to answer telephone and in-person requests, and provide health information materials and guidance to members of their communities.



“You learn to know what your community wants and you stock what they need.”



Librarians must evaluate, select, organize, and store information as well as provide a range of health information services on a limited budget. According to the American Library Association, library budgets have increased modestly or remained flat for the past several years. For example, Barbara Henry, a medical librarian at the Community Health Library in Wilmington, DE says she would rather fill her shelves with the most usable information and not necessarily the most diverse. Her users are primarily White Americans over the age of 50, although she is trying to reach out to minorities by carrying material focused toward African American and Hispanic American populations. “You learn to know what your community wants and you stock what they need,” says Henry. “Most of our people seek out information on chronic diseases.”

For minority groups, access to high quality health information is of particular importance. According to a recent report from the Institute of Medicine entitled *Unequal Treatment – Confronting Racial and Ethnic Disparities in Health Care*, “A large body of published research reveals that racial and ethnic minorities experience a lower quality of health services, and are less likely to receive even routine medical procedures than White Americans even when variations in factors such as insurance status, income, age, co-morbid conditions and symptom expression are taken into account.” The report states that these differences are associated with greater mortality among African American patients.

Yet many members of minority groups are unaware of the health information resources that their local libraries provide. For example, Hispanic Americans, especially those new to this country, are often reluctant to approach public libraries since they are unaware that most public library services are free. Outreach to these minority groups is critical, which a number of libraries are accomplishing by working with schools, churches, senior citizen centers, and other community-based programs. Librarians have tried a number of approaches to reach out to these groups. For instance, The Health Library in Palo Alto, CA publishes a community health calendar listing upcoming seminars, lectures and free health services that is sent to over 10,000 community groups, clinics and doctors’ offices. Many of its materials are published in Spanish and Chinese, the languages of the two largest minority populations that it serves.

“Most of our people seek out information on chronic diseases.”

The quality of health information on the Internet varies, and must be evaluated to ensure that it is current, reliable, and unbiased. The Internet and its wealth of health information is a particularly valuable tool for helping minorities learn more about common, chronic illnesses and wellness programs. Internet usage among minority consumers is growing and they need to evaluate the information they find. Librarians can help them to do this. Between December 1998 and September 2001, Internet use among African Americans and Hispanic Americans increased at annual rates of 33 and 30 percent respectively. White Americans, Asian Americans and Pacific Islanders experienced annual Internet usage growth rates of approximately 20 percent during these periods (Department of Commerce, 2001).

Many minorities only use the Internet at libraries.

Minorities use the Internet at libraries in greater numbers than the rest of the population. About 19 percent of African Americans and 14 percent of Hispanic Americans use the Internet at public libraries. In fact, for a number of minorities the public library is the only place they can access the Internet. Just over 19 percent

of African Americans and 16 percent of Hispanic Americans use the Internet solely at the library. Slightly over 20 percent of library Internet users have household and family incomes of less than \$15,000 per year (National Telecommunication and Information Administration, NTIA, 2002).

To help librarians do a better job of providing health information services to minorities, the American Association for the Advancement of Science (AAAS) secured a grant from the National Institutes of Health's Science Education Awards Program. The Healthy People 2010 Library Initiative is designed to provide minorities and other consumers who seek health information at their public libraries with the latest medical information in accessible and easily understandable formats.

As part of the project, AAAS is developing seven plain-language booklets explaining the science behind chronic illnesses of particular significance to minority groups. These



illnesses include diabetes, hypertension and asthma. The text of the plain language booklets will be made available on the Web site so that librarians can download and print topics as needed. A tool kit for librarians will contain resources such as posters, bookmarks, tabletop displays and other materials to help promote the booklets to minority groups. Additional items will be included in the toolkit based on field-testing and feedback from librarians.

Many minorities, especially African Americans and Hispanic Americans, do not have easy access to health care information. If they do, the material is often written above the general population's reading level, making it difficult for minority audiences, some of whom have low literacy skills, to understand.

To eliminate this obstacle, the American Association for the Advancement of Science (AAAS) secured a grant from the National Institutes of Health's Education Awards Program. With this funding, AAAS launched The Healthy People 2010 Library Initiative in October 2000. This five-year project is designed to provide minority groups and other consumers easy access to current, reliable information on selected health topics at their local public libraries.

AAAS expects to accomplish many goals with The Healthy People 2010 Library Initiative. It hopes to learn how public libraries disseminate health information to the public; to encourage library outreach efforts to make minority groups aware that their local libraries provide helpful information and resources; to improve outreach efforts by informing minority groups that their local library is a health care resource; and to improve minority groups' knowledge of important health care topics.

WHAT IS THE Healthy People 2010 Library Initiative?

How can this program help me as a librarian?

This initiative will allow librarians to reach out to their communities' minority groups and provide them with invaluable health care information that would not otherwise be accessible. Librarians will be able to:

- Provide new sources of information on common chronic illnesses among minorities.
- Learn how other consumer health information centers across the U.S. address common challenges and share solutions with each other.
- Provide outreach materials that will make it easier to reach minority audiences.

What kind of health information materials will be provided?

A toolkit will contain seven plain language health-based booklets, displays for library outreach programs in low-income communities, access to PDF files of project materials, and audio files with scientist interviews. Key topics covered will include diabetes, hypertension, asthma, infectious diseases, and AIDS. The information will be presented in an easy-to-understand format so that it is accessible to a wide array of target audiences.

The Internet may contain an endless supply of health information, but it is hard to determine whether or not that information is accurate or unbiased. The general public—especially minorities—continues to seek assistance when it comes to important health care information. The Healthy People 2010 Library Initiative can help librarians to disseminate this important health care literature to the people who need it most.



The Healthy People 2010 Library Initiative has five primary goals:

- 1 To increase the quality and years of healthy life and eliminate health disparities for all minority groups, including African Americans, Hispanic Americans and Native Americans.
- 2 To better educate minorities about common and often chronic health problems such as diabetes and high blood pressure that occur at higher percentages in their communities.
- 3 To educate minorities about the science behind chronic illnesses in plain language information booklets. The booklets, written and/or reviewed by minority scientists and medical professionals, will be developed in tandem with writers who can translate technical information into easy-to-understand information.
- 4 To give librarians valuable information resources and tools that they can disseminate and use with consumers who come to the library for health information.
- 5 To improve outreach efforts to minorities through promotional materials such as posters, countertop displays and bookmarks that will inform them about the wealth of health information and services libraries can provide.



This booklet was developed as an introduction for librarians to the Healthy People 2010 Library Initiative and to share with librarians the resources and information gathered during the first phase of the project. Much of this material comes from a literature review of online and print resources that examine some of the issues librarians face in delivering health information services. The review provides seven key findings and reference materials that support and explain them.

This booklet also contains research gathered from a brainstorming session, interviews with public and consumer health librarians, and focus groups with members of minority groups. It discusses an array of resources and the ways in which public, hospital and medical libraries work cooperatively to meet the public's growing demand for health information.

A REVIEW OF CURRENT LITERATURE

This literature review was undertaken as part of an initial needs assessment for the Healthy People 2010 Library Initiative. The purpose in reviewing the literature was to discover how public libraries disseminate health information to the public; to define the role of other libraries, resources and organizations in this process; and to provide helpful information and potential resources to public and health librarians.

Findings from the literature search and discussions with librarians confirmed that the public's demand for health information has steadily increased over the last two decades and escalated exponentially over the last five years. When MEDLINE first became available to the public on the Internet without fees on June 26, 1997, searches increased from seven to 120 million in its first year (Hollander, 2000, 62). By the year 2000, searches had almost doubled again to 220 million per year. One third of these MEDLINE searches are by members of the general public (Wood, 2000, 315).

It was estimated in May 1999 that sixty million American adults were using the Internet each month, with those seeking health information accounting for approximately 40 percent of this usage (Scherrer, 2000, 50). Librarians said that many of the consumer health information users are over 50 years of age and that they want to improve their quality of care by having better treatment information available.

Electronic databases of print materials searched included Library Literature, ERIC and MEDLINE. The primary search terms were consumer health information and libraries, or public libraries. The search terms were adjusted for each database. Although a few articles were found as full-texts online, several libraries were visited to locate the printed articles. These efforts yielded over 60 print articles on various aspects of this topic dating back to 1980. Only information published in the last six years (1996-2001) is included in this review. An Annotated Bibliography of References is arranged

chronologically starting with the most recent information. Citations and annotations are arranged alphabetically by author within each year.



SEVEN KEY FINDINGS from the Literature Review

The literature review provides a wealth of information on libraries' current consumer health efforts and points out a number of valuable resources for librarians.

1

Consumers report that health information found through libraries is valuable and affects their health care decisions.

Pifalo, et al (1997) conducted a study on users of the Consumer Health Library at the Delaware Academy of Medicine to see what positive effects emerged. A questionnaire was sent to 270 consumers who used this service during 1995. Many consumers who used the service were repeat-users and recommended it to others. Over 83 percent of the respondents indicated that, if asked, they would be willing to pay for the service.

Some of the other findings include:

- **Improved knowledge of health information:**

Ninety-four percent of study participants indicated that they learned more, and 47 percent felt that they better understood information from their health provider.

- **Reduced anxiety about health issues:**

Fifty-two percent felt that their anxiety level was reduced, while less than 10 percent felt that their anxiety increased.

- **Took positive action to address health care concerns:**

Many health information library users reported that they took new action due to what they learned through a library. Here's a synopsis of their actions:

- Asked additional questions (52%)
- Brought new information to their health care provider (41%)
- Made a decision about treatment (36%)
- Made a change in lifestyle (20%)
- Improved compliance with instructions (18%)
- Sought a second opinion (18%)
- Made an appointment to see a health care professional (12%)

2

Much of the health information available in print and in electronic formats is written for a level well above the individuals using it.

In her article on helping public library patrons find medical information, Jana Allcock points out that "...literacy levels of medical information need to be evaluated in accordance with your user populations' literacy needs" (Allcock, 2000, 24). Medical information is often complex and written at an education level beyond what the general public can understand. Librarians must be sensitive to the users' needs and capabilities when guiding them to sources of information.

Baker & Wilson also suggest that the majority of consumer health materials are beyond the reading ability of the general public. It calculated the Flesch-Kincaid readability formula for several items found among the health materials in a public library. Although 8th grade is the readability level at which most materials intended for the general public are targeted, the consumer health reading materials they examined ranged from the 10th through 19th grade reading level. Their results are consistent with other studies that have looked at the readability of health materials on topics such as HIV, cholesterol and asthma (Baker and Wilson, 1996, 124). Most of these materials are written at grade 10 or higher.

3

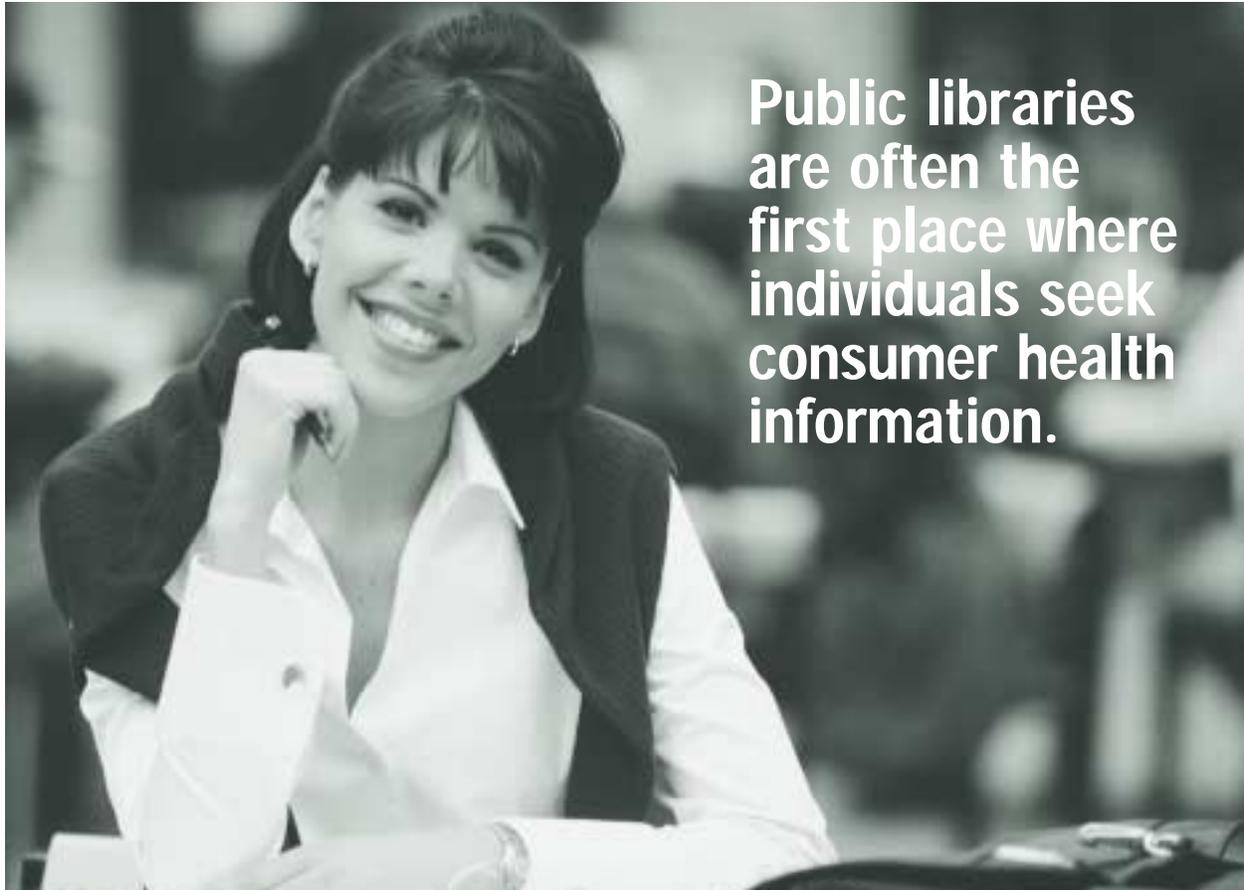
Public libraries are important providers of consumer health information.

In focus groups conducted by the Reference Point Foundation, all groups reported using libraries for general health information needs, and 60 percent of the participants said that libraries were among their preferred sources of health information (Derring, 1996, 213). Public libraries are often the first point of access for individuals seeking consumer health information.



Although the Internet is making a great deal of health information widely available, not all of this information is reliable, accurate and unbiased. Consumers continue to require assistance in sifting through the sheer volume of information available and in selecting reliable sources.

Among the electronic resources that some public libraries make available to their users are two health databases designed for the general public: Gale's Health Reference Center and EBSCO's Health Source Plus. Both databases contain current full-text sources of health information. As they use CD-ROM technology, public libraries sometimes have a dedicated workstation to house one of these consumer health databases.



Many public libraries assist their users in finding reliable health information online by providing lists of evaluated sources on the library's Web site. Some of these online databases can only be made available in library branches because of licensing restrictions, while others can be accessed remotely. Public libraries also provide links from their Web sites to evaluated health Web sites (See sidebar on Web sites referenced in the literature review, page 19).

In large urban communities where the population is diverse and the literacy level of users is varied, public librarians face another problem. Hispanic Americans, African Americans and other minority groups often have many questions about their health, but their English language skills make it difficult for them to access the desired information (Derring, 1996, 211). A number of health information videos and books are available in Spanish but may not be kept in the library's consumer health information section. It is particularly critical, then, that librarians train their staff to help people for whom English is their second language.

To meet the growing demand for health information in their communities, some public libraries have established specialized consumer health information centers or services; others have established health Web pages or health links on their library Web sites to help consumers; and some have formed liaisons with hospital or health sciences libraries. Fortunately, public libraries do not have to go it alone. With online access, even the smallest public libraries have an array of resources available.

4

There are lessons to be learned from libraries that have established a Consumer Health Information Service.

Librarians who want to start a consumer health information service will find helpful information in Mary Gillaspay's article, "Starting a Consumer Health Information Service in a Public Library" (Gillaspay, 2000, 5-19). She provides guidance for planning and implementing such an initiative.

The Consumer And Patient Health Information Section of the Medical Library Association (CAPHIS) Web site has a searchable database of its members who have reported data on staff, space allocation, collections, budget, etc. It also includes an important policy statement on "The Librarian's Role in the Provision of Consumer Health Information and Patient Education," which provides a useful standard (CAPHIS, 1996). There is also a link to a section developed by medical librarians entitled, "How Do You Set Up and Run a Consumer Health Library?" CAPHIS has other links to bibliographies and materials that will be of interest.

The Health Information Center at the Wheaton Regional Library, Montgomery County, MD Public Libraries, was established in 1989 and was one of the first consumer health information centers in an American public library (See sidebar on Wheaton's Health Information Center, page 11).



A new training video, "The Librarian Is In; Facing Modern Consumer Health Issues in the Public Library," with its accompanying handbook, will be helpful to public librarians. The video includes five vignettes of simulated reference interviews dealing with topics such as doctors' credentials, cancer treatments, alternative medicine, pharmaceutical products and emotional users. Print and Web resources are mentioned in the interaction between librarian and user, and they are summarized by the narrator. The facilitator's handbook also contains helpful information. The video and handbook could be used in training sessions or for self-study by individual librarians (see [Helms, 2001] in the Annotated Bibliography).

Public libraries may wish to compare their health collections to selected lists or core collections. There are several such lists, including the following: Alan Rees' book contains a minimal core collection, which will be of interest to small public libraries (Rees, 2000). Horne (1999) provides his perspective on a minimal collection for a consumer health service.

The Brandon/Hill Selected List of Print Books and Journals for the Small Medical Library sets a standard for health sciences libraries. Although the full selected list contains 630 books and 143 journals, the minimal core list of 81 titles may be of greater interest to public libraries.

CREATING A SUCCESSFUL HEALTH INFORMATION CENTER: How Maryland's Wheaton Public Library Did It

In May of 1987, residents in Montgomery County, MD participated in a community information needs assessment survey. They were asked which of eleven topics they most needed information about. Residents said they wanted a place to obtain personal health care information without having to visit a doctor's office or health care clinic.

Fourteen years later, the Wheaton Library's Health Information Center (HIC) provides an extensive amount of information to community members, and it receives phone calls from consumers and librarians all over the country searching for health care information sources. The HIC is funded through a Library Services and Construction Act Grant and Montgomery County. It is housed in what was once an unused 1,500 square foot section on the main floor of the Wheaton Public Library.

"People always seem to come back to us once we've helped them before," says Sandy Negro, manager of the HIC since 1997. "By helping people to conduct health care research, we are able to help them prevent such things as non-essential surgery or drug reactions. People tell us that the information they found has helped them in many ways."

HIC makes the most of a lean operating budget. Not including salaries, \$16,000 is allocated for journals; \$35,000 for reference titles, circulating books and videos; \$20,000 for separate titles

owned solely by the center; \$15,000 for titles owned at other local libraries; and \$5,000 for DOCLINE.

The HIC houses approximately 7,700 circulating books and 250 videos, as well as 900 reference books and 100 journal subscriptions. Also available are over 100 pamphlet boxes containing information on various diseases and conditions such as cancer, arthritis, high blood pressure, diabetes, heart disease, pregnancy and nutrition. Library cardholders can access such databases as MEDLINE; Health Reference Center; Academic, and the Health & Wellness Resource Center; and Resource USA.

Outreach to minority groups is an important part of HIC's promotional efforts because they are often unaware of the services that the Wheaton Public Library provides. "Getting the word out to minorities is extremely difficult," says Ms. Negro. "They are not typical library users and aren't used to having public libraries that they can use. We need to

network in small groups and get people who work in the field, particularly social workers, to be knowledgeable about us."

HIC has a variety of programs designed to raise awareness of its services to minority communities. It recently hired an outreach coordinator to further help raise its visibility among community members. Its current outreach efforts include:

- Placing HIC brochures in libraries throughout Montgomery County.
- Educational programs on health care topics including blood pressure screenings and health insurance counseling.
- Articles for local newspapers written by library staff explaining which public libraries offer health care information.
- Afternoon homework assistance to first through eighth graders and outreach to parents about HIC through the students.

As one of the oldest health care information centers in the country, Wheaton's staff has a great deal of knowledge about how to set up, stock and maintain health care information in a public library. Ms. Negro provides training for librarians on health education resources and is a frequent speaker on this topic.

For further information contact: Health Information Center, Wheaton Library, 11701 Georgia Avenue, Wheaton, MD 20902
Phone: (240) 777-0678
www.montgomerylibrary.org/healthinfo/hic.asp

5

Regional networks, consortia and other partnerships play an important role in meeting the health information needs of consumers.

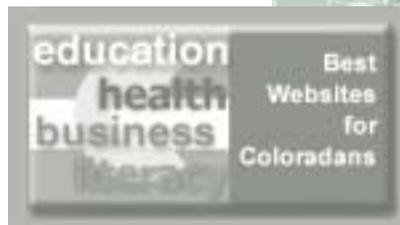
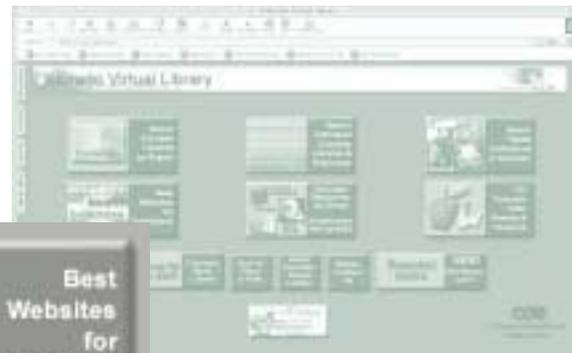
Many regional networks, consortia and other partnerships were created to help meet the health information needs of consumers. Only a few of these are discussed here. Many of these focus on the health information needs of the citizens of a state or geographic area, but, since they are usually Web-based, the information is available to others as well. (URLs for the Web sites described below can be found on page 19).



NetWellness is a Web-based consumer health information service that focuses on the rural health and information needs of Ohio residents. Founded in 1995, NetWellness is now a key statewide service. Partnerships and alliances with many types of organizations at the state and local levels, including collaboration with public libraries, have made NetWellness an important health information resource for consumers. An interesting feature of NetWellness is its Minority Health Center, which includes

prevention and wellness information presented as healthy living tips, health topic focus areas, news and views, Web links and “Ask an Expert” links. The intent is to reach out to African Americans and other minorities in Ohio’s rural Appalachian population (Guard et al, 2000, 1996, 374-381).

The Access Colorado Library and Information Network, ACLIN and the Colorado State Library have created a virtual library for the residents of Colorado, which provides access to library holdings, digital collections and selected, reliable Web resources. One of the features of this virtual library is a Best Web sites for Coloradans section; it includes 13 subject areas, one of which is health and medicine. Librarians from public, academic and special libraries in Colorado have worked together to evaluate and select these sites to assist consumers in finding reliable online health information (Blankenship & Walsh, 2000, 27-30).



New York Online Access to Health (NOAH) represents a collaboration among four libraries and two other partner organizations to provide consumer health information to New York City residents. With the help of volunteer librarians who serve as page editors, NOAH evaluates and provides access to full-text information on a range of medical and health topics. In order to meet the needs of New York City users, NOAH provides materials in English and Spanish. The authors report that as of June 1999, the NOAH site was accessed about 500,000 times monthly, with 25 percent of the activity linked to the Spanish pages (Gallagher et al, 2000, 53-65).



HealthWeb is a collaborative project in which 22 academic health sciences libraries are working together to organize and evaluate Web sites providing medical information (Scherrer, 2000; Redman et al, 1997, 47-51). The goal is to develop a shared resource providing access to Internet sites with health-related information. Each librarian develops and updates an in-depth resource on one subject to share with other libraries.



Although HealthWeb was originally intended to serve as a resource for health care professionals, it has expanded to serve consumers as well. Information targeted for consumers is provided for most topics. HealthWeb continues to evolve, adding new capabilities such as Boolean searching, which make it a helpful resource for public librarians trying to assist their users in locating reliable and accurate health and medical information on the Internet.

6

Hospital, health sciences and medical libraries are increasingly providing consumer health information services to the public.

Hollander (2000) conducted a survey of health sciences libraries in publicly and privately supported medical schools to determine the extent to which academic health sciences libraries provided services to meet the health information needs of the general public. Although most of the 105 libraries that responded indicated that they “did not actively promote use of the library by the general public,” 62 libraries (98.4%) affiliated with publicly supported medical schools, and 30 libraries (71.4%) affiliated with privately supported medical schools, indicated that they provided “access and service to all, including the general public” (Hollander, 2000, 64).



An example of how one medical library reaches out to the public can be found at the Consumer Health Information Service of the Preston Medical Library at the University of Tennessee Medical Center in Knoxville, TN. Martha Earl, reference coordinator, describes the services and outreach the library provides to the public (Earl, 1998, 44-46). Librarians answer telephone and e-mail queries through the library Web site and in-person questions as well. Consumers may visit to do their own research and receive assistance from the staff.

Not all academic health libraries have the resources to provide this type of outreach since they must first meet the needs of their primary users, but increasingly they are reaching out to the public. Howard University in Washington, DC recently opened a new state-of-the-art health sciences library in which every seat is wired for Internet access. Among its innovative features is a telemedicine room that allows diagnoses through video work stations, as well as a problem-based learning classroom in which digital technology allows students to view virtual reality and computer simulated medical and health situations. The library also has a community resources center.

Some medical and health sciences libraries provide services directly to the public, and others work in partnership with public libraries using interlibrary loans, faxes, etc. or referrals initiated at public libraries to provide these services to consumers.



Hospital libraries are also increasingly providing services to the public or working with public libraries to meet this need. The Santa Rosa Cancer Library and Resource Center in Northern California is an example of how one hospital reached out in its community to meet a need (Grossman, 2000, 29-37). The library helps patients and families obtain information about diagnosis and treatment, local and electronic support groups and the latest information about the physical and psychological pressures of a cancer diagnosis. It is a valuable community resource to which librarians can refer their users.

Lambremont (1997) described how the Veterans Administration (VA) Medical Library in Alexandria, LA expanded its Patient Education Resource Center to incorporate consumer health information services. Moeller (1997) discusses the establishment and services of the Consumer Library at Overlook Hospital in Summit, NJ. Started in 1982, it is one of the first consumer health services to be established in a hospital library. Spatz (2000) describes the Planetree Health Resource Center in rural Oregon, which provides a model for service in a small community. Where direct and public access to the hospital library is not feasible, community public and hospital libraries often network by phone, fax and Internet to share resources and provide better services to the public.



MODEL CONSUMER HEALTH LIBRARIES

PUBLIC LIBRARIES

C. Everett Koop Community Health Information Center

19 South 22nd St.
Philadelphia, PA 19103
(215) 563-3737
Andrea Kenyon
kenyon@collphyphil.org

Consumer Health Information Service

Toronto Reference Library
789 Yonge St.
Toronto, Ontario
M4W 2G8
(416) 393-7056
Susan Murray
www.tpl.toronto.on.ca/
uni_chi_index.jsp

Consumer Health Library New Hanover Co. Public Library

201 Chestnut St.
Wilmington, NC 28401
(910) 341-4385
Dan Horne
Dahorne@nhc.gov.com

Wheaton Public Library

11701 Georgia Ave.
Wheaton, MD 20902
(240) 777-0678
Sandy Negro
negros@mont.lib.md.us
www.montgomerylibrary.org/
healthinfo/hic.asp

Planetree Health Resource Center

98 North 17th St.
San Jose, CA 95112
(408) 977-4549
Candace Ford
www.planetreesanjose.org

UNIVERSITY, HOSPITAL OR MEDICAL CENTER LIBRARIES

Christiana Hospital Library

3506 Kennett Pike
Wilmington, DE 19807
(302) 661-3471
Barbara Henry

Consumer Health Library at the Delaware Academy of Medicine

1925 Lovering Ave.
Wilmington, DE 19806
(302) 656-1629
P.J. Grier, Director of Libraries
consumer@delamed.org
www.delamed.org/

The Health Library

2-B Stanford Shopping Center
Palo Alto, CA 94304
(650) 725-8400, (800) 295-5177
Nora Cain
health.library@medcenter.
stanford.edu

The Hopwood Library

UPMC Shadyside
5230 Centre Ave.
Pittsburgh, PA 15232
(412) 623-2620
Michele Klein-Fedyshin, MSLS,
Manager of Library Services
kleinm@msx.upmc.edu

The Learning Center, Northwestern Memorial Hospital

Suite 3-304, Galter Pavilion
251 East Huron St.
Chicago IL 60611-2908
(312) 926-5465
Mary L. Gillaspay, MLS, MS
Health Learning Center Coordinator
mgillasp@nmh.org
www.nmh.org/healthlearningcenter

Mayo Patient Education Center

Siebenf Subway, 200 First St. SW
Rochester, Minnesota 55905
(507) 284-3114
Margo Kroshus
Kroshus.Margo@mayo.edu

Planetree Health Resource Center

Mid-Columbia Medical Center
200 E. 4th St.
The Dalles, OR 97058
(541) 296-8444
Michele A. Spatz, M.S.L.S., Director
mickeles@mcmc.ne

Preston Medical Library

1924 Alcoa Highway, Drawer U-111
Knoxville, TN 37920-6999
(865) 544-9525
Doris Prichard, Director
dprichar@mc.utmck.edu
www.utmedicalcenter.org/library/

Robert Mulreany Health Sciences Library

99 Beauvoir Ave.
Summit, NJ 07902-0220
(908) 522-2119
Kathy Moeller, MLS, AHIP
Manager, Library & CME Services
kathy.moeller@ahsys.org

The Santa Rosa Cancer Library and Resource Center

Santa Rosa Memorial Hospital
Cancer Library & Health Resource
Center
3555 Round Barn Circle
Santa Rosa, CA 95403
(707) 522-6883
Janie Grosman, Medical Librarian
www.selu.com/cancerlib/
patient_libraries.htm

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The National Library of Medicine (NLM) and other government agencies are valuable sources of consumer health information.

The National Library of Medicine (NLM) offers many services that provide access to health and medical information. It also helps meet the needs of consumers who access these resources directly on the Web or through their public libraries.

MEDLINE is the world's largest collection of published medical knowledge. According to NLM statistics, MEDLINE users are approximately 36 percent librarians and researchers, 34 percent health care professionals and 30 percent general public (Modlin, 1998, 40-42). An updated study found that the general public continues to represent one-third of MEDLINE users (Wood, 2000, 315).

Recognizing that consumers needed a more user-friendly resource, the NLM developed MEDLINEplus, which was launched in October 1998. Full-text resources are provided. Consumer language is matched to medical terminology, a simple search interface is provided, and preformulated MEDLINE searches created by librarians are included for each health topic, making it much easier for consumers to search the MEDLINE database. MEDLINEplus is a well-organized, selective resource that helps consumers find reliable sources, whether they are searching the Web themselves or seeking assistance in their public libraries (Miller et al, 2000, 11-17).



In October 1998, the NLM launched a pilot project to help NLM decide how to work with public libraries to promote consumer access to health information and to generate information that would assist NLM and the National Network of Libraries of Medicine (NN/LM) in the future. Forty one public libraries and 11 supporting medical libraries participated. The study concluded that



NLM is committed to providing better access to health information.

the NN/LM can assist public libraries in becoming better sources of health information for the public. The study also confirmed that NLM and the NN/LM need to work with a variety of organizations and groups as well.

The study results suggested several ways in which NLM could assist public libraries in the future. Many of these are being implemented, including providing training or resources to help public librarians use NLM databases, a Web-based training course for public librarians, promotional materials and other initiatives. NLM is clearly committed to providing better access for consumers to health information and continues to develop new ways to accomplish this goal (Wood, 2000, 314-322). SERHOLD, another service, is briefly described in the Annotated Bibliography. (For details, see Press, 2000).

A valuable Web-based health information resource comes from the U.S. Department of Health and Human Services (HHS). Healthfinder works with other federal agencies and provides a gateway to reliable consumer health and human services information from selected Web sites, databases, online publications, federal agencies and other organizations.

Two other government agencies supporting consumer health information resources should be noted. The National Institutes of Health (NIH) has an online consumer health information page, which is an expanding collection of the most requested NIH publications grouped by Institute. The Healthy People 2010 Gateway has health and human services information as well as links to other sites.

While a great deal of progress has been made to improve the delivery of consumer health information services in libraries, there is much more to be done. Librarians know that one of their biggest challenges is reaching out to community members. Often, they partner with community groups to accomplish this effort. Libraries with the resources have established outreach programs to reach minorities. One goal of the Healthy People 2010 Library Initiative is to help librarians develop outreach programs welcoming minority consumers to public libraries which inform them that libraries are valuable resources of health information.



HEALTH-RELATED WEB SITES FOR FURTHER INFORMATION

www.healthlit.org, the Web site for The Healthy People 2010 Library Initiative, also provides links to other information resources such as health Web sites and audio on health topics.

www.fairfax.va.us/library, Fairfax County, VA Public Library's Web site, features "Well Connected," an extensive listing of online databases with links to reliable sources of health information.

hobbspublib.leaco.net is where you can find Health Links at the Hobbs, New Mexico Public Library Web Site. It also has links to WebCat and other consumer health information.

www.caphis.mlanet.org is the Web site of CAPHIS, the Consumer and Patient Health Information Section of the Medical Library Association. It provides links to Healthfinder, or **www.healthfinder.gov**, a Web site developed by the Department of Health and Human Services that works with other federal agencies. Healthfinder supplies online publications, Web sites, support groups and non-profit organizations that produce health information for the public. Another CAPHIS link can be found at **www.caphis.mlanet.org/resources/ARchin.html**; this is a core collection of 50 health titles that is updated biennially by the ARCHIN Resource Task Force.

www.tpl.toronto.on.ca/TRL/centres/chis/index.html is where you will find The Toronto Reference Library Consumer Health Information Service's Web site, which was established in 1991 with four partner organizations. It links to literature such as "Developing a Consumer Health Information Service: A Practical Guide" and is continually updated.

www.netwellness.org or NetWellness, is a Web-based consumer health information service focusing on the health and information needs of Ohio residents.

www.aclin.org will take you to a virtual library created by The Access Colorado Library and Information Network, ACLIN and the Colorado State Library for the residents of Colorado. This site provides access to library holdings, digital collections and selected, reliable Web resources.

www.NOAH-health.org is where you can access the New York Online Access to Health (NOAH). This represents a collaboration among four libraries and two other partner organizations to provide consumer health information to New York City residents.

www.healthweb.org or HealthWeb, is a site dedicated to an array of health topics that span from alternative medicine to women's health.

www.nlm.nih.gov includes PubMed, MEDLINE, and other databases. The Brandon/Hill Selected List of Print Books and Journals for the Small Medical



Library, which is updated biennially, can be accessed through PubMed.

www.nlm.nih.gov/medlineplus is MEDLINEplus's Web site. It provides the consumer with health topics, drug information, dictionaries, directories and other important health resources.

See **www.nih.gov/health/consumer** to find The National Institutes of Health's online consumer health information page, which is an expanding collection of the most requested NIH publications grouped by Institute.

www.consumer.gov, or The Healthy People 2010 Gateway, has health and human services information as well as links to other health-related sites.

ANNOTATED BIBLIOGRAPHY / REFERENCES

2002

Institute of Medicine. (2002). *Unequal Treatment – Confronting Racial and Ethnic Disparities in Health Care*, 3.

National Telecommunications and Information Administration (NTIA) and the Economics and Statistics Administration. (2002). A Nation Online: How Americans Are Expanding Their Use Of The Internet.

<http://www.ntia.doc.gov/ntiahome/dn/html/anationonline2.htm>

2001

Helms, Mary E. (2001). Consumer Health Training Available. *The Unabashed Librarian*, 119:16-17.

The Librarian Is In: Facing Modern Consumer Health Issues in the Public Library is a consumer health training video intended to help librarians in public libraries and other settings deal with consumer health questions. The video and handbook are available from the ICON Consortium, University of Nebraska Medical Center for \$25. Contact Mary Helms at (402) 559-7099, (402) 559-5498 fax, or mhelms@unrnc.edu.

Hill, D.R. and Stickell, H.N. (2001). Brandon/Hill Selected List of Print Books and Journals for the Small Medical Library. *Bulletin of the Medical Library Association*, October 2001, 89(2):131-53.

This selected list of 630 books and 143 journals is intended to serve as a selection guide for health sciences libraries. Public libraries will find it useful since it also includes a minimal core list of 81 titles. This is the 19th version of the list, which has been biennially updated for 36 years. The list can be accessed on the Web through PubMed at www.nlm.nih.gov.

2000

Allcock, Jana C. (2000). Helping Public Library Patrons Find Medical Information – The Reference Interview. *Public Library Quarterly*, 2000, 18(3/4):21-27.

As public libraries are often the first access point for additional information resources on health and medical topics, the reference interview between librarian and user becomes critical. This article provides information that will help public librarians conduct a successful reference interview and ensure that their users receive adequate resources and follow-up support while protecting their confidentiality.

Blankenship, Lisa and Walsh, Mary. (2000). Consumer Health on the Web: Helping Coloradans Find the 'Good Stuff.' *Colorado Libraries*, Fall 2000, 26(3):27-30.

This article describes the efforts of the Colorado State Library and Access Colorado Library and Information Network (ACLIN) to provide consumer health information access to all Colorado citizens. Through the Colorado Virtual Library (www.aclin.org), access is provided to library holdings, digital collections, and selected and reliable Web resources.

Gallagher, Patricia E., Markovich, Kristine, and Neri, Rita. (2000). NOAH (New York Online Access to Health): Accurate, Timely, Unbiased, Bilingual. *Public Library Quarterly*, 2000, 18(3/4):53-65.

NOAH is a Web site (www.NOAH-health.org), which is a collaboration between four libraries and two other partner organizations to provide consumer health information to New York City residents. To meet the needs of its users, NOAH attempts to provide both English and Spanish materials. With the help of volunteer librarians who serve as page editors, NOAH evaluates and provides access to full-text information on a range of medical and health topics.

Gillaspy, Mary L. (2000). Starting a Consumer Health Information Service in a Public Library. *Public Library Quarterly*, 2000, 18(3/4):5-19.

This article provides helpful information and advice for librarians who are interested in establishing a consumer health service in a public library. The author outlines a step-by-step guide for planning and implementing a consumer health service in a public library. She also discusses Web sites and other resources, and she provides other useful background information.

Grosman, Mary Jane. (2000). A Cancer Library and Health Resource Center: Resource for the Community. *Public Library Quarterly*, 2000, 18(3/4):29-37.

The Santa Rosa, California Memorial Hospital Cancer Library and Health Resource Center was developed to create a community resource for cancer information. This is an example of how hospitals have reached out to their communities to provide consumer health information. This article describes the facility's development, staffing, funding, materials, services and outreach programs.

Guard, R., Fredericka, T.M., Kroll, S. et al. (2000). Health Care, Information Needs, and Outreach: Reaching Ohio's Rural Citizens. *Bulletin of the Medical Library Association*, October 2000, 88(4):374-81.

Hollander, Sue M. (2000). Providing Health Information to the General Public: A Survey of Current Practices in Academic Health Sciences Libraries. *Bulletin of the Medical Library Association*, January 2000, 88(1):62-69.

This article reports on a survey of 148 publicly and privately supported academic health sciences libraries affiliated with medical schools in the US and Canada to determine level of access and services provided to the general public. The full text of this article can be found online through Pub Med at www.nlm.nih.gov.

NetWellness is a Web-based consumer health information service that focuses on the rural health and information needs of Ohio residents. Initially a regional demonstration project in 1995, NetWellness is now a key statewide service. Partnerships and alliances with many types of

organizations at the state and local levels, including collaboration with public libraries, have made NetWellness an essential health information resource. NetWellness can be found on the Web at www.netwellness.org. The full text of this article can be found online through Pub Med at www.nlm.nih.gov.

Miller, Naomi, Lacroix, Eve-Marie, and Backus, E.B. (2000). MEDLINEplus: Building and Maintaining the National Library of Medicine's Consumer Health Web Service. *Bulletin of the Medical Library Association*, January 2000, 88(1):11-17.

MEDLINEplus is a Web-based consumer health information resource made available by the National Library of Medicine (NLM). Designed to provide consumers with a well-organized, selective Web site, it provides access to reliable full-text information and directs consumers to dictionaries, organizations, directories, libraries and clearing-houses for answers to health questions. Consumer language is matched to medical terminology. It can be found at www.nlm.nih.gov/medlineplus.

Press, Nancy Ottman. (2000). SERHOLD and the Public's Access to Health Information. *Bulletin of the Medical Library Association*, July 2000, 88(3):269-272.

When eager consumers of health information find citations in MEDLINE, they may not be able to easily find the article. The author describes SERHOLD, an NLM database that can help librarians locate copies of the articles for their users. The database includes the 1.3 million health serial holdings of more than 3,000 health libraries. The author suggests creative ways that hospitals and other health libraries might work with public libraries to provide better access to their users via this database. The full text of this article can be found online through Pub Med at www.nlm.nih.gov.

Rees, Alan M., Editor. (2000). *Consumer Health Information Services*. Phoenix, AZ: Oryx Press, 6th edition.

This book provides a wealth of information for librarians and consumers of health information. The minimal core collection in Chapter 8,

“Supportive Professional Literature,” will be of special interest to small public libraries. Chapter 11 includes over 1,500 pamphlets, booklets, brochures and leaflets on a wide variety of health-related topics. The extensive annotated listing of selected print health resources keeps this book in high demand in most public libraries.

Scherrer, Carol S. (2000). Health Web: Both A Resource for Public Librarians and a Prototype for Collaboration Among Libraries. *Public Library Quarterly*, 2000, 18(3/4):47-51.

HealthWeb is a project by 22 academic health sciences libraries to collaboratively organize and evaluate Web sites providing medical information by developing a shared resource. Since evaluating information available to library users on the Internet is a constant challenge for librarians, this project can serve both as a prototype and a resource for public librarians who are trying to assist their users in locating reliable and accurate health and medical information on the Internet. HealthWeb is found on the Web at www.healthweb.org.

Spatz, Michele A. (2000). Providing Consumer Health Information in the Rural Setting: Planetree Health Resource Center's Approach. *Bulletin of the Medical Library Association*, October 2000, 88(4):382-8.

The Planetree Health Resource Center has been providing consumer health information in a rural area of Oregon since 1992. This community-based consumer health library is affiliated with a small rural hospital called Mid-Columbia Medical Center. Embracing the Planetree philosophy of humanizing, personalizing and demystifying the delivery of health care, it provides a model for consumer health information delivery and outreach.

Wood, Fred B., Lyon, Becky, Schell, Mary Beth, et al. (2000). Public Library Consumer Health Information Pilot Project: Results of a National Library of Medicine Evaluation. *Bulletin of the Medical Library Association*, October 2000, 88(4):314-322.

In October 1998, the National Library of Medicine (NLM) launched a pilot project to learn about the role of public libraries in providing health information to the public and in generating information that would assist NLM and the National Network of Libraries (NN/LM) to effectively work with

public libraries in the future. Forty-one public libraries and 11 supporting medical libraries participated. This article reports on the project and its evaluation.

1999

Horne, Daniel C. (1999). A Medical Library for the Public: Starting and Running a Consumer Health Library. *North Carolina Libraries*, Fall 1999, 57(3):110-13.

This article contains observations and advice based on the author's first year of experience directing the Coastal Consumer Health Library in Wilmington, NC. The author has also included a Suggested Core Collection, which librarians may wish to compare with other lists of core collections noted in this bibliography. Its Web site is www.nhrmc.org/choose, then Coastal Consumer Health Library.

Ulmer, Erma D. (1999). ARCHIN to Coordinate Health Information. *Arkansas Libraries*, December 1999, 56(6):39-40.

The Arkansas Consumer Health Information Network (ARCHIN) is a cooperative effort of numerous libraries and health care agencies. It was created in 1998 to meet the special health needs of the Arkansas population. The ARCHIN Resource Task Force updates bi-annually a Core Bibliography of Consumer Health Books, which can be found at the CAPHIS web site: www.caphis.mlanet.org/resources/ARchin.html.

1998

Baker, Lynda M., Spang, Lothar, Gogolowski, Christine. (1998). The Provision of Consumer Health Information by Michigan Public Librarians. *Public Libraries*, July/August 1998, 37(4):250-5.

The authors report the results of a 1997 survey administered to Michigan public librarians. Information was collected on the services that are currently provided by public libraries to meet the consumer health information needs of public library users in Michigan.

Earl, Martha F. (1998). Caring for Consumers: Empowering the Individual. *American Libraries*, November 1998, 29(10):44-6.

This article describes how the Preston Medical Library in Knoxville, TN reaches out, through its Consumer Health Information Service, to provide health and medical information to consumers by telephone, in-person, and through e-mail queries to the library's Web site.

Goldberg, Beverly. (1998). Is There a Librarian in the House? *American Libraries*, November 1998, 29(10):54.

This article, which is also from the issue entitled "Information Is the Best Medicine: Libraries and Health," briefly describes some public library-based consumer health information centers that developed as a result of users' specific needs.

Liu, Lily and Mann, Edwina Walls. (1998). Consumer Health Bibliography: A List of 50 Core Books. *Arkansas Libraries*, October 1998, 55(5): 9-15.

This list is updated bi-annually (see Ulmer, 1999) by the ARCHIN Resource Task Force, and the most current version is available online at the CAPHIS Web site:
www.caphis.mlanet.org/resources/ARchin.html.

Modlin, Melanie. (1998). Medical Questions? Medline Has Answers. *American Libraries*, November 1998, 29(10):40-42.

This article describes Medline and some of NLM's earlier efforts (as of 1998) to reach out to health information consumers, and how Medline helps public libraries meet that need.

Voge, S. (1998). NOAH – New York Online Access to Health: Library Collaboration for Bilingual Consumer Health Information on the Internet. *Bulletin of the Medical Library Association*, July 1998, 86(3):326-34.

Established in 1994, NOAH is a collaborative project that is of special interest because it provides access to consumer health information in Spanish as well as English. For a further discussion of NOAH and its usefulness to public libraries, see Gallagher et al, 2000, above.

1997

Lambremont, Jane A. (1997). Consumer Health Information Services in the Hospital Setting. *Medical Reference Services Quarterly*, Summer 1997, 16:61-7.

This article discusses the experiences of the Veterans Administration Medical Library in Alexandria, LA and how it provides consumer health information and patient education services in a hospital library.

Moeller, Kathleen A. (1997). Consumer Health Libraries: A New Diagnosis. *Library Journal*, July 1997, 122(12):36-8.

The author describes the establishment and services of the Consumer Library at Overlook Hospital in Summit, NJ. Established in 1982, it is one of the first consumer health services in a hospital library. She also reports on the results of a customer satisfaction survey conducted in 1993.

Pifalo, Victoria; Hollander, Sue M. and Henderson, Cynthia L. (1997). The Impact of Consumer Health Information Provided by Libraries: the Delaware Experience. *Bulletin of the Medical Library Association*, January 1997, 85(1):16-22.

Librarians at The Delaware Academy of Medicine's Consumer Health Library in Wilmington, DE conducted a study of 270 users to assess the impact and value of providing consumer health information in libraries. The results reinforced the value of the information to the users and demonstrated several positive effects.

Redman, P.M., Kelly, J.A., Albright, E.D. et al. (1997). Common Ground: the HealthWeb Project as a Model for Internet Collaboration. *Bulletin of the Medical Library Association*, October 1997, 85(4):325-30.

This article discusses the Health Web Project (www.healthweb.org) originally started cooperatively by twelve health sciences libraries to improve access to health-related Internet resources for health care professionals. The vision of the project was to serve as a model for other collaborative Internet projects. For an update on the project, see Scherrer, 2000.

1996

Baker, Lynda M. and Wilson, Feleta L. (1996). Consumer Health Materials Recommended for Public Libraries: Too Tough to Read? Public Libraries, March/April 1996, 35:124-30.

This article addresses the readability of consumer health information materials. The authors report the results of a study in which they discovered that the readability level of all the items they examined exceeded the eighth grade level, which is the level at which most materials intended for the general public are targeted. They also discuss some earlier studies conducted on the readability of consumer health information materials.

Consumer and Patient Health Information Section (CAPHIS) of the Medical Library Association (MLA). (1996). The Librarian's Role in the Provision of Consumer Health Information and Patient Education. Policy Statement for Medical Library Association and the Consumer and Patient Health Information Section (CAPHIS/MLA). February 1996. *Bulletin of the Medical Library Association*, April 1996, 84(2):238-9.

This policy statement can also be found online at the CAPHIS web site: www.caphis.mlanet.org.

Derring, Mary Jo and Harris, John. (1996). Consumer Health Information Demand and Delivery: Implications for Libraries. *Bulletin of the Medical Library Association*, April 1996, 84(2): 209-216.

In 1995, the Department of Health and Human Services supported an assessment of consumer health information demand and delivery, which was conducted by the Reference Point Foundation. This article summarizes findings from this study, highlighting those that suggested a role for libraries in providing and interpreting health information.

Guard, Roger, Haag, Doris, Kaya, Birsan, et al. (1996). An Electronic Consumer Health Library: NetWellness. *Bulletin of the Medical Library Association*, October 1996, 84(4):468-77.

This is a description of the initial development of Netwellness. For an update on this project, see Guard, 2000 above.

HEALTHY PEOPLE 2010 LIBRARY INITIATIVE

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Founded in 1848, the American Association for the Advancement of Science (AAAS) is the world's largest federation of scientific and engineering societies, with over 270 affiliated organizations. AAAS members include more than 138,000 scientists, engineers, science educators, policymakers, and interested citizens. The Association's goals include:

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 - Advancing education in science.
 - Increasing public understanding and appreciation for the importance of the methods of science in human progress.
- AAAS also is the publisher of Science magazine.

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- Informal science and mathematics education with community-based organizations.
- Libraries, science museums, and technology centers.

EHR projects and activities include a children's science and mathematics cyber club, science media fellowships, science and technology summer internships in government and business for students with disabilities, and a science radio show.

Any interpretations and conclusions contained in this report are those of the authors and do not represent the views of the AAAS Board of Directors, the Council of AAAS, its membership or the National Institutes of Health.



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