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Tammy L. Mays

Issue Editor

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Introduction

Tammy L. Mays

Making consumer health information accessible to the public has enhanced and empowered lives. How do we know this is fact? This unique issue will look at the research to show how librarians have been the change agents who cultivate and maintain a web of relationships and resources needed to be advocates for consumer health information. There are many unique challenges that librarians face to improve health literacy by promoting well-written, easy to understand, reliable, quality health information. There is no special formula for implementing consumer health information services or models, but this issue is dedicated to addressing the imperative topic of translating formal and informal research initiatives into practice. This compilation assembles the best practices for consumer health information services and building healthy bridges through innovative and sometimes surprising partnerships.

In part 2 of the series “Consumer Health Issues, Trends and Research,” contributors address the many facets that comprise consumer health information services. Applicable Research in the 21st Century promotes creative partnerships and models between agencies and library institutions and delivers strategies for achieving health literacy in a variety of communities. Nancy Ottman Press and Mary Diggs-Hobson met the health information needs of a faith ministry community by meeting people where they are, not where we want them to be, and by developing an innovative model of health information provision to a new community. Stephanie Weldon discusses the need for collaboration and marketing to ensure the library remains viable to its internal and external audiences—health professionals, hospital
administrators, and the public. Erica Burnham and Eileen Beeny Peterson were moved by their experiences with patients at the Patient Resource Centre of the Montreal Neurological Hospital and chronicle the international movement to raise awareness of the necessity for health literacy. Angela Ruffin, Keith Cogdill, Lalitha Kutty, and Michelle Hudson-Ochillo’s research analyzed fifty-three funded consumer health outreach projects through the National Network of Libraries of Medicine and discovered that as a result of collaborations between health sciences librarians and public librarians, the public library began to perceive hospital and academic libraries as resources for medical information. Michele Spatz tells health information professionals how to formulate strategies for successful partnerships with community agencies such as parks and recreation agencies, social service agencies, and public health departments. Andrea Kenyon describes a pilot project to test the feasibility of bridging the digital divide by placing trained volunteers at Internet access sites in community locations. Gail Kouame, Margo Harris, and Susan Murray capture the perceptions and expectations of library staff members from both sides of the reference desk, both patron and librarian. Mary Gillaspy covers current issues like the number of health news items available in all media and the fact that physicians and nurses are spending less time providing health information and patient education during regular office visits, which impacts the provision of health information in public libraries. Lastly, Candice Smith, Kara Logsden, and Maeve Clark highlight their innovative project at the Iowa City Public Library in Iowa, in which they educated the community on finding and using good health information resources on the Internet.

The authors, representing medical, academic, government, and public libraries as well as library school faculty, have been selected because of their reputation, expertise, and successes in the consumer health arena. I hope that this focused collection of actionable approaches, testimonials, and prescriptions will serve as a valuable resource for librarians with an interest in providing consumer health services at their institutions.

Acknowledgements

The author wishes to express her sincere appreciation to Jenifer Grady, director of the ALA-Allied Professional Association, American Library Association, and Elaina Norlin, program officer of the Institute of Museum and Library Services, for their positive energy, encouraging words, and editorial advice.
Providing Health Information to Community Members Where They Are: Characteristics of the Culturally Competent Librarian

Nancy Ottman Press and Mary Diggs-Hobson

Abstract
Since all people make health decisions, all people need health information. Currently most people do not get health information from libraries; nevertheless, librarians can play an important role in the provision of health information if they listen carefully to community needs, develop cultural competence, and work with community partners. Librarians must collaborate to provide services where people are: physically, culturally, linguistically, educationally, and in many other senses. An example is given of a partnership between the librarian at Mars Hill Graduate School and the African Americans Reach and Teach Health Ministry that provides information services to faith communities in the Puget Sound area. Concepts discussed are summarized in a proposed list of cultural competencies for librarians.

Health information is distinctive in its universal necessity. When asked how frequently reference desk questions are health related, one public librarian quipped that they were “second only to automotive related” requests. While not everyone owns an automobile, 100 percent of our actual and potential patrons have bodies and minds, and 100 percent of those patrons make decisions about health. We may well be able to generalize about the individuals who are currently pursuing information in our libraries, but not everyone who needs health information is coming into our libraries. In fact, Tu and Hargraves (2003) found that in 2000 the majority of a sample...
of Americans (62 percent) never sought information about a health concern; instead they were passive recipients of health information (from the media, etc.). Thus, in the provision of consumer health information we, as librarians, might have our greatest opportunity to affect every member of the community. This article will focus on universal service to individuals and communities.

How do librarians meet health information needs of individuals and their communities? By meeting people where they are, not where we want them to be. We cannot fulfill everyone’s health information needs if we set criteria for who should be served, where and when the service should take place, what information should be provided, and who should provide it. All parameters of library service should be questioned in the light of who is served—the community and its individuals. Once we understand the “who,” the answers to “where and when,” “what,” and “who serves” follow naturally.

The authors are involved in a partnership that can serve as an example of health information provision to a new community. The library at Mars Hill Graduate School (a graduate-level divinity and counseling school) is partnering with the African Americans Reach and Teach Health (AARTH) Ministry to help faith communities in the Puget Sound area fulfill the health information needs of their congregations. The librarian in this case is white and the community members are African American, but the principles to be discussed in this article apply whenever a librarian seeks to provide service to a patron who identifies with a different community.

In the AARTH–Mars Hill collaboration, the questions and answers are as follows:

Who should be served? Members of African American faith communities in the Puget Sound area, along with their families, friends, and anyone else who affiliates with those communities.

Where and when should information services be offered? In churches on Sunday mornings, at evening faith meetings, at church-sponsored health fairs and health classes, and whenever someone looks on AARTH’s and the various churches’ Web sites for health information.

What information should be provided? Information on the specific health issues that disproportionately affect African Americans, short health articles to go on the back of church bulletins, culturally appropriate information, links to programs that will read Web pages aloud, information on how to find good health information, etc.

Who should provide the information? Not the librarian; instead, community leaders, pastors, health professionals, and volunteers have the direct information-sharing role. The librarian is critical but in the background.
Since outreach to this extent might be unfamiliar for some librarians, we can learn from other professions that also are reaching out to every person in the community. Two pertinent professions are health care and public education, the first because of the shared subject matter of health, and the second because educators, like librarians, enable access to information. Health care and education already have extensive outreach literatures that can be of value to librarians embarking on universal service. Most of the research cited in this paper comes from the literature of those two fields.

Who Is Served?

When we provide health information, whom are we serving? Within the United States, “between 1985 and 2030, the proportion of children from non-white, non-Anglo-European groups will rise from 28% to 41%” (Lynch & Hanson, 1998, p. 8). The population we are serving now—and will be serving in the years ahead—gets more diverse every day. Moreover, the foregoing statistic just covers the aspects of race and country of origin; it does not take into account language, culture, religion, reading ability, sexual orientation, health practices, learning style, disabilities, critical thinking style, information assimilation preference, and decision-making methods—to mention just a few characteristics. These characteristics may be shared by entire communities, may pertain only at the individual level, or may be both communal and individual. With our usual patrons, those who have been entering our libraries for years, we may have known exactly how to provide service. When we enlarge our service to encompass everyone in the community, we can no longer make assumptions about either the individuals or the community from which they come. As an example, the racial disparity in information use is marked; African American women use printed news media on health 50 percent less than average and computer-based resources 60 percent less than average (Nicholson, Grason, & Powe, 2003).

One of the oldest principles in educational theory (dating back to the Greeks) is that people learn and remember best when new information is related to current knowledge and experience (Wittrock, 1986). Therefore, to provide health information in the most effective way, we must relate the health information we provide to our patrons’ own health experience and knowledge, which may be entirely different from our own.

Some librarians have become extremely knowledgeable about certain ethnic, racial, or cultural groups. An excellent example of this refined knowledge is offered by Ellen Howard in EthnoMed (ethnomed.org), a Web site that describes characteristics that impact health care for a variety of refugee and immigrant communities in the Seattle area: Amharic, Arab, Cambodian, Chinese, Eritrean, Ethiopian, Lao, Mexican, Mien, Oromo, Somali, Soviet Jewish, Tigrean, Ukrainian, and Vietnamese. The Web site discusses health beliefs, languages, family and kinship structure, etiquette, immigration is-
sues, domestic conventions, and experience with Western medicine, among other issues. We can, and should, use such sources to become knowledgeable about the various cultures in our communities; however, even such a remarkable Web site only touches a corner of all cultural characteristics and obviously only covers a few of the thousands of world cultures. The lesson is that we will never know as much about a person or community as that person or community knows. The study of a variety of cultures simply enables us to understand that a wide range of differences exist: “Cultural sensitivity cannot mean knowing everything there is to know about every culture that is represented in a population to be served. At its most basic level, cultural sensitivity implies, rather, knowledge that cultural differences as well as similarities exist” (Anderson & Fenichel, 1989, pp. 8–9).

The first step is to acknowledge that we do not know much about others. In light of our infinite ignorance, what can we do to be sensitive and respectful of our patrons? The next step is to be aware of our own values and biases, and the third is to work with our patrons to find acceptable methods and materials. For example, librarians are fond of (or are biased toward) drawing Venn diagrams to explain Boolean logic and search strategy. The educational system taught us that our profession values two-dimensional representations of complex concepts on rectangular surfaces; the use of maps is another example. Once we understand and accept that we are biased toward two-dimensional, rectangular representations, we may then be more understanding of a patron who shuns the two-dimensional representation and says, “Can you just tell me what this is all about?” or “Can you just show me how to use that search box?” or merely has a confused and frustrated look when presented with a Venn diagram. In order to perform the search, the patron does not necessarily need to understand Venn diagrams. Fortunately, most librarians have other teaching methods ready: we can perform a sample search so that the patron sees, in practice, what results are obtained with the various Boolean operators; or we can make up some simple, verbal rules like “putting an ‘and’ between words means you will get fewer things; putting an ‘or’ between words means you will get more.” Venn diagrams are merely our educational system’s culturally biased means of representing a concept that can be represented in a variety of different ways. We need to rid ourselves of the criterion that only patrons who understand Venn diagrams can be taught how to use search boxes in databases or that only patrons who can read maps can find their way to the clinic.

Once we acknowledge and accept our ignorance and biases, the next step is to ask questions. This step, often called community assessment (Burroughs, 2000), can start with research such as that in EthnoMed, but eventually it needs to involve personal contact with the community through questionnaires, interviews, focus groups, or simple conversations. With the African Americans Reach and Teach Health Ministry, we sent out question-
naires that asked about the demographics and needs of each congregation. The results gave us comparable information for the various groups. Then we interviewed at least one church leader, usually the pastor, to find out how he or she characterized the community—what needs, strengths, and interests were present, as suggested by SWOT theory (Strengths, Weaknesses, Opportunities, Threats, n. d.). For example, one church sponsors a regular workshop called “Undoing Racism,” offered by the People’s Institute for Survival and Beyond, indicating a strong interest in, and probable knowledge of, racial justice in the health care field. Another pastor mentioned several times the need for a Web page reader on the AARTH home page so that people who cannot read can still hear every page, which was a signal that nontextual media of many varieties might be useful in the community.

While questionnaires and planned interviews are invaluable, so are direct, immediate questions and answers. Before a project planning meeting, the librarian asked if it would be all right to invite a colleague to accompany her. AARTH’s director told her that this was not appropriate at the beginning of the partnership. Because the librarian asked, and because the director answered forthrightly, a mistake was avoided. The reason for the director’s response brings to light the importance of respect for cultural differences and similarities in relationship building. It was necessary for AARTH to establish its presence as a strong community player before bringing in other institutional partners.

Finally, in the process of developing mutual understanding with individuals and communities, we must also develop a trusting relationship. Howell even emphasizes the importance of a “pleasant” interaction as a crucial setting for honest and trusting discussions of health (Howell, 2003). An effective way of developing trust is to find similarities or mutual values. Institutionally, Mars Hill Graduate School, as a seminary and counseling program, and AARTH, as a health ministry, both emphasize the faith-health connection. Individually, the librarian and the AARTH leaders found unity in the belief that faith communities should go beyond prayer to action when the health of the community is threatened.

Therefore, in order to understand whom we serve we must

1. Acknowledge that we do not know as much about other people or communities as they know about themselves
2. Recognize our own and our community’s biases
3. Open ourselves up to learn about and from other people and other communities
4. Work to develop a trusting relationship with individuals and communities

Once we increase our understanding of people in our community, the other questions follow more easily.
WHERE AND WHEN IS INFORMATION OFFERED?

Our next question is, Where and when should we provide health information services? The majority of Americans are not getting their health information in libraries. Some of the most important sources of health information are families, friends, health care professionals, the Internet, television, radio, newspapers, magazines, and books (Hudson & Watts, 1996; Tu & Hargraves, 2003; Diaz, Griffith, Reinert, Friedmann, & Moulton, 2002). Few studies of health information-seeking patterns of the general public mention libraries.

The public health field has long recommended that, in order to reach new people, institutions must go where they are—do not expect them to come to you. Public health educators regularly communicate with people in beauty parlors (Booker, 2000), at food banks, at needle exchange sites, on billboards, on television, on the job site, etc.

Librarians often express the bias that it is “good” to use a library, but limiting health information services to those who want to and can use a library sets up a barrier. In our work with the African American faith communities, we find that it is “good” to go to the church for information. Information of all kinds received at church has a higher chance of being culturally appropriate and of blending with community values and way of life. When information is provided in a way that is compatible with current values and patterns, it has a greater chance of being used (Rogers, 2000).

Especially in the African American community, barriers exist between the usual information sources and consumers (Matthews, Sellergren, Manfredi, & Williams, 2002). We must find ways to remove those barriers (Zarcadoolas, 2000) and must never blame people for not using (to our biased eyes) perfectly fine resources that are inaccessible for others. One way of reaching across the information-access barrier is the faith community. Churches have been shown to be particularly effective sites for health education (Winett, Anderson, Whiteley, Wojcik, Winett, & Rovniak et al., 1999), since African Americans look to their churches for community resources more than people in other communities.

The AARTH-collaborating churches have already taken responsibility for health issues; most have health ministries or means by which members of the congregation who are health-care professionals share their expertise in the church. The AARTH director recommends that librarians make sure information is provided in an environment that is comfortable for the community—a place that is accessible so that people do not have to dress up, get in the car, or take a bus. For the AARTH community, that is often the church, where people feel more comfortable asking questions about health and can get answers in their own language. Not only did we expect the information to be shared where people already are, but even the partnership meetings were held at sites suggested by AARTH rather
than by the librarian (except when specific resources in the library were needed). In other words, the librarian went to the community and did not expect the community to come to the library.

Given the growing use of the Web and media for health information (Diaz et al., 2002; Tu & Hargraves, 2003), the place where health information may best be provided is in every individual’s own home. One might postulate that a librarian could make the greatest impact on the quality of health information in many communities by providing excellent library services to the health reporter at the local TV station, the local newspaper, or a health Web site developer. Certainly, librarians who are involved in the creation of excellent health Web sites, such as NOAH, MedlinePlus, or EthnoMed, have a long reach.

We have a choice: Do we attempt to change the information-seeking traditions of every community member, or do we offer learning opportunities to the current providers of health information? The chances for effectiveness are infinitely greater when we help a few people do better what they already want to do well rather than attempt to change everyone.

In order to understand where and when to provide health information services we need to

1. Find out where individuals and communities are currently seeking health information
2. Encourage those information-seeking patterns
3. Improve current sources of information where people already are

**WHAT HEALTH INFORMATION?**

What health information should we make available? Needs assessments are perhaps more effective in this area than any other. However, we must be sure our needs assessments are broad, not just asking what information people need but digging deeper to ask if people even feel a need for information. Using the Stages of Change model, if the community does not perceive a need for information, any information provided is useless until we help people go from precontemplation to contemplation and onward (Rogers, 2000). Since only 38 percent of Americans seek information for a health condition (Tu & Hargraves, 2003), in a needs assessment we might very well find that the need is to inspire the desire to seek information rather than to actually provide any information. The role of the librarian is then as a change agent.

AARTH and its partner churches had already perceived the need for information. The AARTH pastors and congregations were concerned about the health disparities of African Americans and saw information as one means to address the problems. Steps can be taken to influence a community to recognize need (Witte, 2000), but we will be more effective if we start with needs that are already expressed by the community. In our
needs assessments with AARTH partners, the same health topics arose again and again. By creating Web pages that address those topics, we show the compatibility of the AARTH Web site with current need.

An unexpected need that arose during our needs assessment was for a specific form rather than specific content. Churches need short (half-page to one-page) health information pieces that can fit on one page of the church bulletin. Many topics were of interest, if only they could be effectively and appropriately covered briefly. In addition, the information had to come from an agency that would not require permission or payment for reproducing.

Librarians tend to be effective seekers and finders of whatever information is needed. Recent work in New York Online Access to Health (NOAH, www.noah-health.org) and MedlinePlus (www.medlineplus.gov) has greatly enhanced the variety of materials available in terms of reading level, language, and format. Somewhat more difficult to find is culturally appropriate information. For example, African Americans experience greater morbidity and mortality for many diseases than their white counterparts; therefore information written for African Americans should recognize the more serious nature of diseases.

In finding health information for AARTH Web pages, it was often necessary to forego librarians’ standard inclusion criteria (such as that used by MedlinePlus) and instead find Web sites written by and for African Americans. For example, MedlinePlus requires that a “list of advisory board members or consultants is published on the site” (U. S. National Library of Medicine, 2004), but for AARTH, authority may be more appropriately established by the endorsement of African American community organizations. In the case of the AARTH project, the librarian published, on the Web, a treatise on HIV/AIDS by a respected and well-loved local African American physician; the actual content could have been found on many sites, but since Dr. Moses has the ear of the community, his words can make a much greater impact.

At times the information needed is not readily available. At that point the role of the librarian expands beyond finder and collector to creator or advocate for creation (Alpi & Bibel, in press). For example, Ellen Howard of EthnoMed wrote successful grants that paid for the translation of materials.

Therefore, to provide the needed information, librarians should

1. Use a variety of methods for discovering information needs—in terms of topic, level, format, etc.
2. Seek out current materials that match those needs
3. Where needed materials are not extant, advocate or arrange for the creation of materials or compilations
Who Provides Health Information?

The final question is, Who should serve the health information needs? Randall-David (1989, p. 26) has listed therapeutic agents or people whose help is sought in various communities:

- **Mainstream White American** Counselors, Psychiatrists, Psychologists, Social workers, Ministers
- **African American** Ministers, Root workers, Voodoo priests
- **Native American** Medicine men, “Singers”
- **Mexican American** Curanderos
- **Puerto Rican** Espiritistas, Santerios
- **Cuban** Santerios
- **Southeast Asian American** Herbalists, Family/friends, Diviners
- **Haitian** Voodoo priests

Note that librarians are not on the list; librarians are not necessarily seen as people to whom one should look for health information. If our goal is to ensure the provision of good health information, it may not be necessary for librarians ever to be seen by the broad community as the source of health information. Librarians may be the best people at discerning information need and finding appropriate information to fulfill that need, but others may be better at interfacing with the individual or the community. The method by which librarians can help communities is through partnerships, where a community sees the librarian as a help in fulfilling community needs, and the librarian sees the community’s organizations and individuals as a means of carrying out the library’s goals. Community partnerships such as this form the backbone of public health interventions (Briggs, 2003; Strategies for Success, 2001). Community leaders and respected members of a community are the most effective facilitators for the adoption and learning of information-seeking skills (Rogers, 2000). An individual learns best when the person imparting the information is similar to the learner and can model behavior and skills using methods and materials that are mutually familiar (Witte, 2000).

In the case of AARTH, a community organization recognized the need for better information and recognized that a librarian would be an important asset to the organization. The librarian has been involved in developing and using needs assessments, creating a Web site that helps the community explore topics of interest, finding culturally appropriate resources that fulfill stated needs, developing curricula for training sessions, and training representatives from each faith community who will, in turn, train the rest of their congregations. But at no time is the librarian the “face” of the information. The needs assessment is printed on the community organization’s
Perhaps the most critical role for the librarian in a community partnership for health information is to champion universal access and help lower the barriers. For example, normal agency policies and procedures can be barriers for people who are not familiar with the bureaucratic culture (Press et al., 2003). National Library of Medicine (NLM) funding provided for computers for the AARTH project. However, the funding agency required that AARTH buy equipment, then submit receipts for reimbursement, which can take several weeks. The AARTH director was stymied because AARTH had no cash in hand to pay for equipment in the first place. At that point, it was the partner librarian’s cue to see what other arrangements could be made. In this case, the library advanced funding for some of the equipment from the library budget and, more critically, the librarian lobbied—even hounded—the funding agency to change the funding mechanism. While the librarian may not be the direct provider of health information in a universal access setting, advocating for the community and negotiating with bureaucracy are necessary alternate functions.

Therefore, in determining who should provide health information, librarians should

1. Determine who is currently providing health information
2. Partner with those people or organizations in such a way that the partners are the direct community contacts
3. In the partnership, act as advocate as well as information expert

**Conclusion**

We librarians are ideally placed to provide health information effectively to all members of our varied communities:

- We know how to carry out the necessary research to learn about new communities and people.
- We tend to be sensitively responsive rather than prescriptive.
- We instill trust.
- We know information literacy theory and practice.
- We regularly think of alternative methods (for example, synonyms) rather than single answers.
- We can find the varied information to fulfill a wide variety of needs.
- We have a strong service orientation that accepts others getting credit for the information we find.

By mixing together these strengths with methods and skills described in the literature on health and on education, librarians can
• Serve every member of the community
• Provide information where and when it is most needed and best assimilated
• Find the best information to fulfill needs
• Ensure that the information is offered by those most able to ensure its use

Speaking to individuals or groups about their personal health and physical well-being is an exercise in humility and honor. When a partnership works, and when the librarian approaches the community with humility, the community grants the librarian permission to ask questions and provide answers that lead to a deeper understanding of the social-cultural fabric of people without being considered intrusive. The librarian is in the unique position of being a conveyer of information and facilitator of relationships and partnerships. For the librarian, a community partnership can bestow the honor of mutual trust, understanding, and regard.

Characteristics of the Culturally Competent Librarian

Many fields have codified cultural competence. It may be time for librarianship to adopt a similar code, such as that suggested below. Since the health field already has developed several codes, the following has been adapted from the health literature (Health Resources and Services Administration, 2002; National Center for Cultural Competence, 1999–2004; U.S. Department of Health and Human Services, 1999; Sue & Sue, 2003; Sue, Arredondo, & McDavis, 1992; American Psychological Association, 1993; Sutton, 2000).

I. Attitude

1. The culturally competent librarian is one who is becoming culturally aware and sensitive to his or her own heritage, along with the cultural heritage of others.
2. The culturally competent librarian can conduct self-assessment and is aware of how his or her own values, biases, attitudes, and beliefs may affect different or minority patrons.
3. Culturally competent librarians are comfortable with differences that exist between themselves and their patrons.
4. The culturally competent librarian values
   a. Individual identity: what makes individuals unique
   b. Group identity: reference base that may incorporate family, race, ethnicity, gender, religion, age, etc.
   c. Universal identity: common aspects that all share as human beings.
II. Knowledge
1. The culturally competent librarian seeks to possess specific knowledge and information about the particular group with which he or she is working.
2. The culturally competent librarian seeks to understand the sociopolitical system with respect to its treatment of minorities.
3. The culturally competent librarian has knowledge and understanding of characteristics of information seeking and information use.
4. The culturally competent librarian is aware of institutional barriers that prevent minorities from gaining information.

III. Skills
1. The culturally competent librarian generates, sends, and receives a wide variety of verbal and nonverbal responses.
2. The culturally competent librarian develops and implements institutional strategies in partnership with communities, including setting goals, assessing need, developing a diverse work force, and evaluating services.
3. The culturally competent librarian can incorporate his or her values and knowledge into aspects of policy-making, administration, practice, and service delivery.
4. The culturally competent librarian is able to play a variety of partner roles:
   a. consultant—serving as resource person to other professionals and/or minority populations
   b. outreach—moving out of libraries and into patrons’ communities
   c. ombudsman—accompanying partners and patrons through bureaucratic mazes and procedures
   d. facilitator of indigenous support systems—structuring activities to supplement, not supplant, existing information-seeking systems.

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References


Collaboration and Marketing Ensure Public and Medical Library Viability

Stephanie Weldon

Abstract

The increased demand for consumer health information over the past twenty years has inspired many to usurp the job of the librarian. Health professionals are writing articles about the provision of health information for their patients. Newspaper and magazine articles tout the importance of health information companies as the means through which the public can pay for access to health information. Hospital libraries are closing at a rapid rate throughout the United States, with hospital administrators citing lack of funding as the reason and viewing the medical library as a drain on the hospital bottom line. Collaboration and marketing are two elements that ensure the library remains viable in the eyes of health professionals, hospital administrators, and the public. As librarians, we have collaborated with each other for years with tremendous results. Now is the time to publish these successes in the professional literature of health administrators and professionals and in newspapers and popular journals. Now is the time for the public and health professionals alike to realize the contributions librarians have made and are making on the consumer health front.

The Colorado Consumer Health Information Librarians Listserv (CCHILL) formed in 2002 and began holding quarterly meetings (National Network of Libraries of Medicine, Midcontinental Region, 2004). The CCHILL group’s mission is to establish personal connections between public and medical librarians. They meet regularly to share ideas and innovations, develop relationships, talk with professionals who have similar

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consumer health missions in their institutions, and develop collaborative projects for the mutual benefit of the institutions and the public they serve. CCHILL has met primarily in the greater Denver area. It is hoped that the rest of the state will implement CCHILL groups as geographic areas permit.

A poster session hosted by a Douglas County and a Denison Memorial librarian at the 2004 Colorado Association of Libraries Conference will demonstrate the efficacy of CCHILL and encourage more partnerships within the state. A letter will be sent from the MidContinental Regional Medical Office at the University of Utah to hospital administrators who support their libraries, thanking them for their support and detailing the benefit that the hospital library provides to their institution. The Colorado Council of Medical Libraries Advocacy Committee will be presenting an award at the Colorado Hospital Administrators Conference to administrators who support their hospital library. These three initiatives in 2004 will hopefully provide a start to a sorely needed marketing campaign for libraries.

Involvement in the CCHILL group has demonstrated the need for marketing the positive impact of collaborative librarians not only to fellow librarians but also to administrators and the public. Many hospital administrators support the development of consumer health collections by their medical librarians and realize the importance of marketing their services to the public via the public libraries. At the same time, most hospital administrators do not realize the importance of having a consumer health collection. They do not let their librarians leave the library for training, much less explore the idea of a collaborative partnership with a public library. This lack of vision on the part of some hospital administrators is damaging not only to the librarian but also to the hospital and the patients they serve. Some public library bureaucracies also do not want to commit time or resources to partnering with hospital librarians who want to provide additional services to their public library patrons.

Hospital librarians working in partnership with public librarians have the opportunity to market to the local population. Marketing can be done by way of a public library Web site, which, on the health information page, displays the partnership that exists between them and the local hospital library. For what better and more economical endorsement could a hospital marketing department ask? In 2001 hospital marketing department budgets rose to an average $1.95 million ("Survey: Hospitals’ Marketing Budgets Near $2 Million Mark," 2001). In 1997 the two hospitals that comprise Evanston Northwestern Healthcare, launched a $1 million marketing campaign ("Hospitals Start a Marketing Blitz," 1997). Medical librarians must partner with hospital marketing departments when proposing collaboration with public libraries. With the marketing department on the side of librarians, hospital administrators may see an additional value to the medical library. Hospital administrators will realize that partnership with the public library
is a low-cost ad campaign that says the hospital supports the community and that the county that supports the public library is a friend of the hospital. It is easy and cost-effective marketing that should not be discounted or overlooked.

This collaboration between medical and public libraries is not for the sole benefit of the medical library. The public librarian, who answers many health questions every day, will have a resource in the medical librarian. Difficult search questions can be referred to the medical librarian, as can patrons who want access to more resources and expertise than may be available at the local library. The public library will be seen as a good steward of the taxpayer dollar. It will be endorsing advanced access for patrons to health information from reliable sources. It is in the public’s interest to have service industries working together to provide the best access to health information possible. The public needs to be told of the collaborative efforts of its library.

The CCHILL group is an offshoot of the National Network of Libraries of Medicine, MidContinental Region’s goal to have each state within its six-state (Colorado, Kansas, Missouri, Nebraska, Utah, and Wyoming) region develop collaborative partnerships between medical and public libraries. It is hoped that each state will develop groups that meet in person, on a regular basis, in order for lasting connections to develop.

Wyoming held its first annual symposium in the summer of 2003. Librarians from across the state gathered to make connections, and learn about accessing quality health information for health professionals and the public alike. Public and medical librarians made connections and a listserv was formed uniting librarians from diverse institutions across a state that is primarily rural. The combination of distance and weather make face-to-face meetings a once a year occurrence. The listserv is a way for librarians in Wyoming with an interest in providing consumer health information to collaborate at a distance.

Nebraska has had a partnership in place between public and medical librarians since 1985. The McGoogan Library, the Nebraska Library Commission, and more than seventy public libraries in the state formed the Consumer Health Information Resource Service (CHIRS) (McGoogan Library of Medicine, 2004). This service provides consumer health information to any person in the state of Nebraska. Librarians from McGoogan provided training and materials to public librarians across the state. The CHIRS project has evolved over nineteen years and now provides individualized information packets to patrons requesting information. They also have the public library as the initial point of contact, reinforcing the importance of the local librarian.

Utah also has had a longstanding collaborative effort between public and medical libraries known as the Utah Consumer Health Information Network (UCHIN, 2004). UCHIN is a collaborative project of the Eccles
Health Sciences Library at the University of Utah and the Health Round Table (HEART, 2004) of the Utah Library Association. UCHIN connects people to resources found online and in their local communities. HEART brings together public and medical librarians on a regular basis. A few of the HEART goals listed on their Web site include

- Provide professional development opportunities with content geared toward health information resources for librarians
- Increase awareness and practice of personal healthy choices
- Publicize the round table and attract members by maintaining the HEART home page

Kansas is in the midst of developing a consumer health librarians group that will meet regularly. They have several strong consumer health librarians in their state who are anxious to explore collaborative ideas on a more formal level. Partnerships between public and medical librarians exist on a formal level via the Johnson County Public Library system. It is hoped that this endeavor will serve as model for the rest of the state.

Missouri, the second state to “Go Local” in accordance with the MedlinePlus initiative to connect citizens to local resources, has a history of public and medical librarians working together. The University of Missouri sponsors Community Connections through its extension program. This sponsorship results in local resources being made available to the citizens of Missouri (Community Connection, 2004).

Missouri held its first annual symposium on consumer health in June of 2004. This symposium brought together multitype librarians from across the state who are interested in consumer health. This was an exciting and informative symposium hosted by Mary Ellen Sievert in conjunction with the University of Missouri at Columbia.

Collaboration

The collaborations mentioned above are not new or innovative. Collaboration among librarians from different institutions and environments has been in existence for years (Eakin, 1980; Hollander, 1996). Librarians collaborate. Medical librarians from competing hospitals in the same town participate in DOCLINE (2004) to ensure that the health professionals they serve have quick access to necessary health information. Medical librarians participate in Medlib-L (2004), the listserv for the Medical Library Association. If a medical librarian is having difficulty with a search, a colleague will be asked for assistance, as librarians want to be absolutely sure the best health information is provided to their customers. Consumer health librarians participate in the Consumer and Patient Health Information Section (CAPHIS, 2004) of the Medical Library Association. A librarian can ask a question on the listserv about the best multiple sclerosis educational videos...
Librarians do not work in a vacuum; they freely share information. The Colorado Council of Medical Librarians (CCML, 2004) participates in a consortium whereby members can purchase commercial databases at a greatly reduced cost. Denver Health Hospital recently shut down its library and consequently lost the ability to purchase commercial databases at the CCML group rate. This increase in purchase price came as a surprise to their administration. The MidContinental Region of the National Network of Libraries of Medicine has begun discussion about developing a regional buying consortium between its six states. Barbara Jones, the Missouri liaison, at the University of Missouri, Columbia, for the MidContinental Region, is spearheading this project. This collaborative project will allow small hospital and large academic libraries alike to have access to online resources at a more affordable rate.

Medical librarians must let their administrators know that, because they belong to consortia buying groups, **because they are librarians that collaborate**, their institution has access to more online resources at an affordable rate. Administrators need to know that if they shut down the library this affordable access to information will go away. Administrators must realize that librarians participate in listservs made up of professionals from around the globe. Librarians participate in these consortia and listservs because they want to provide the best service possible at the most affordable rate. Collaborative librarians save their institution money. What seems intuitive to librarians is novel to administrators. We need to market our value to the institution and make administrators realize our worth.

Public librarians providing consumer health information must let their institutions know that they are participating in the CAPHIS listserv in order to collaborate with medical librarians, thereby ensuring that the public receives the best, most current information. Does your public library administrator know that you participate in a listserv sponsored by the Medical Library Association? Do they know that you receive consumer health collection development suggestions and tips on providing outreach? **Share the various collaborations you are a part of with your administrator.** What may seem second nature to you may appear very innovative to the administrator. The citizens your library serves also may be interested in a newspaper editorial stating the ways that the library saves the community money by partnering with local medical librarians to provide current health information and expert searching.

**Librarianship by Any Other Name Is Lucrative**

There is money to be made in the provision of consumer health information. The demand for consumer health information exploded in the 1990s
in conjunction with the mainstreaming of Internet access. Fifty-two million American adults, or 55 percent of those with Internet access, have used the Web to get health or medical information (Fox & Fallows, 2003).

Many for-profit companies are developing health information Web sites. Their advertisement campaigns continue to carry weight with the health professional. When exhibiting at health professional conferences, one routinely has to explain the difference between WebMD and MedlinePlus and why a health professional would bother accessing MedlinePlus for patient information. Pharmaceutical companies sponsor health information portals. Pfizer lists health information resources and suggestions for quality control. Pfizer has also taken a lead in health literacy education, offering monies to support health literacy initiatives in underserved populations (Pfizer, 2004). Merck, to their credit, has made the Merck Manual and other valuable manuals available online in several languages on their Web site (Merck & Co., 2004). Abbott Laboratories has a health information portal that provides consumer health information, while at the same time advertising the drugs they produce (Abbott Laboratories, 2004). The Eckerd drug store developed an online clinical pharmacy whereby one can search drug interactions and find out more about Eckerd. Advertisements permeate the Eckerd Web site, but good information is available (Eckerd, 2004).

Most of these companies are offering quality health information and initiatives to the public. They are doing so because that is what the public wants. At the same time they are advertising their services. Hospitals would do well to follow these giants of industry and give the public what they want. A great basic marketing strategy for those in the health care business is to provide health information to the public. Librarians must make sure they are included in this campaign.

Public librarians are taking train-the-trainer courses from medical librarians on a regular basis. They work with a public that is demanding access to health information, and they want to be prepared to meet the needs of the public. Public librarians may want to write an article for the local newspaper, letting the public know about the amount of training they have received so that they can give the best possible service to their patrons.

Businesses have also developed for the sole purpose of selling health information. Librarians have watched this new wave of entrepreneurship with an element of perplexed amazement. Newspapers and magazines are fed articles from companies seeking to advertise their services. In the Sunday, April 27, 2003, business section of the Denver Post, an article entitled “New RX for Health: Informed Patients—Specific Research Targets Each Case,” by Marsha Austin, business writer, discussed a new company called “Corporate Hearts.” This company charges $1500 for customized health information packets. The article portrays medical libraries in a negative light, indicating that one must “thumb through reams of medical journals trying to find the answer.” Obviously, if indeed the person did thumb
through journals, they did not bother to ask the medical librarian for help. Medical librarians have been providing customized information packets to consumers for years (Exempla Healthcare, 2004). This article gave medical librarians a chance to remind the institutions they serve of the quality and service they provide to customers and physicians at a fraction of the cost.

Some recent articles about consumer health and patient information are also of concern because they completely bypass any mention of the librarian when talking about implementing consumer health centers, finding quality health information, or evaluating health information on the Internet. When articles such as “Consumer Health, Patient Education and the Internet” (Campbell, 2002) state that “Veterans in the field of medical informatics will point out that much of this information is available in print form. However, to get at this information, the health consumer is required to visit medical libraries and sift through volumes of highly specialized, arcane professional literature,” it is a cause for alarm. Obviously, we as librarians have not been aggressive enough in advertising the advances our profession has made in publications such as the Internet Journal of Health.

Other articles of particular concern are those published by health professionals. Some health professionals still do not understand exactly what a librarian does. The health professional may see a need for patient health information and not realize that the librarian meets that need every single day and works to stay updated on the latest patient information resources. The Journal of MedSurg Nursing (VanBiervliet & Edwards-Shafer, 2004) focuses on patient information and decision-making tools. A library for a potential class for seniors, the searching skills of a reference librarian, and MedlinePlus and other NLM consumer databases are mentioned in the article as important tools. However, the fact that librarians can help with the selection and evaluation of patient information tools is overlooked. Surgical nurses, in this article, are being charged with the selection of health information tools. It would be more effective if respective experts in their field practiced their profession. Librarians would never consider taking on the roll of a surgical nurse. Nor do we engage in patient education. Librarians provide access to health information and evaluate the quality of health information. Librarians are very effective in working as part of a team with nurse educators. Taking the burden off the nurse of evaluating and selecting health information tools is the hospital librarian’s job. We need to let health professionals know that we are up to the task.

Another article, in the Journal of Cardiovascular Nursing (Cashen, Dykes, & Gerber, 2004), makes no mention at all of a librarian. This article is about the potential impact of eHealth technology and its ability to empower the patient. The article goes on to discuss various difficulties for the patient with eHealth information resources. Overcoming the difficulties discussed such as literacy, language, lack of access to technology, and educational barriers is the work of librarians. The authors note that community programs can
play a role in providing access to patient information, but no mention is made of the library. Clinicians and eHealth developers are listed as advocates for directing patients to health information, but no mention is made of the librarian. It is worrisome that the author does not know about the multicultural resources that exist on the Internet, like the National Network of Libraries of Medicine Multicultural Resources, which lists most of the top databases for patient health information in multiple languages (National Network of Libraries of Medicine, 2004). The author also did not think to check with a public library to find out what Spanish-language text-based health materials exist for the patient when he said virtually no text-based resources exist in Spanish for disease information.

Are these oversights the fault of the authors, or is it the fault of librarians as a whole? We are busy and efficient. We get the job done without a lot of fanfare. We provide unbiased, objective health information at relatively little cost to any person who visits the public library. Many hospital libraries have consumer health collections or respond to requests for health information from patients and health professionals alike. But we may not be advertising the incredible services we provide effectively enough.

Some libraries are going through budget crises and may not have the time or the resources to advertise. An interesting article entitled “Marketing Library Services: Lessons from the Private Sector” (Amey, 1993) says that marketing in times of severe financial crisis is most important. The author focuses on five major points:

- “the value of the marketing process itself
- marketing as a morale builder
- marketing as a method of clarifying the library’s mission
- marketing as a way to refine targeting
- marketing as a technique for forward thinking” (p. 69).

Some interesting ideas espoused in the article come from the customer service arena in the private sector: “showing interest in the individual, understanding their needs, and adding value to the interchange” (Amey, 1993, p. 71). The author goes on to state that a library patron “does not care about a state of the art computerized library; but they love quick efficient service . . . we must promote the library and its services from the user’s point of view” (Amey, 1993, p. 72). As the author states, we have not adequately shown patrons our true value, which is to “interpret, explain, evaluate, elucidate and above all personalize the search for solutions” (Amey, 1993, p. 72).

We must work to inform health professionals, at all levels, of the importance of the library. A resident once stated in a class entitled “What Your Patients Know,” taught as part of the University of Colorado Health Sciences Center Informatics Program, which the library offers to third- and fourth-year medical students, “pretty soon our patients are going to have access to
as much information as we have.” The response was “they already do have access and you have the opportunity to direct their quest for knowledge to reputable, quality sources of health information. As health professionals you can encourage your patients to visit their medical library. You can build a Web site referring your patients to the medical library’s Web site. You can encourage your administration to keep a hospital library on site and also encourage them to support a consumer health library.”

The authors who fail to mention the library in their articles about providing health information and health literacy still see the library as a place to simply catalog information. They view librarians as lacking in technology and education skills. There are many types of librarians. All are necessary, from the cataloger to those who perform outreach and education. We need to let the health professionals and public know that we are there to assist in providing health information. We make their jobs easier so they can focus on providing care to the patient. We make the hospital administrator’s job easier as we collaborate with the marketing department to ensure that partnerships are made with local public libraries. We can send our patients to the public library for classes on searching the Internet for health information, and the public librarians can send their patrons to medical librarians for access to expert searching.

Our collaborations and innovations must be advertised in the media that the health professionals and public access. As a profession, we are so effective and committed to service that our efforts tend to escape the radar screen of the public as a whole, our administrators, and the people we serve. We must make them aware of our worth.

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Additional Reading


Health Information Literacy: A Library Case Study

ERICA BURNHAM AND EILEEN BEANY PETERSON

ABSTRACT
Concern about health literacy is one factor driving an international movement to develop and disseminate health information that is easy to understand and appropriate for people who have difficulty reading or whose first language is not English. Libraries can work with organizations in their communities to improve the accessibility of materials. Strategies for effective collaboration will be outlined in the context of health literacy promotion efforts. Finally, the role that librarians can play to help deliver appropriate health information, using the example of one patient resource center, will be discussed.

INTRODUCTION
This article will discuss how libraries can participate in the dissemination of plain language and easy-to-read health information to the general public. People should have access to information that is appropriate for their needs and play an active role in their health and well-being. Understanding the information available with respect to health issues increasingly is the responsibility of the patient. Recent surveys evaluating the basic literacy skills of Americans, Canadians, and Europeans have turned up alarming results. Libraries and librarians can contribute to the health of their communities through their involvement with health literacy initiatives and by keeping literacy issues at the forefront.

This article will present a general framework of how illness, stress, fear,
and cultural differences can impact the way in which people understand their health problems—not to mention the health care system itself. The example of one patient resource center will illustrate how libraries can collaborate with the communities they serve to increase understanding of health.

Using criteria familiar to many librarians for evaluating the appropriateness of printed materials, librarians can make management decisions that will benefit users and libraries alike. The concepts of purpose, scope, authority, currency, and audience help us understand who libraries are serving, which organizations are key targets for collaboration, and the purpose of library programs. Hopefully, this practical structure will help others get involved with issues of health literacy.

**What Is Health Literacy?**

Literacy is used in many different contexts today. Libraries have long played a role in basic literacy education and are beginning to carve out their place in the new arena of information literacy. Finding definitions for the terminology of literacy is controversial. It is useful to understand the scope of the issue in order to develop programs and communicate with the community. A few definitions inform our work as librarians.

Literacy is “using printed and written information to function in society, to achieve one’s goals, and to develop one’s knowledge and potential” (National Center for Education Studies, n.d.). Health literacy is “the ability to read, understand, and act on health information” (Pfizer Clear Health Communication, n. d.), and “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (U.S. Department of Health and Human Services, 2000, p. 20). Information literacy is a set of abilities enabling individuals to “recognize when information is needed and have the ability to locate, evaluate, and use effectively the needed information” (American Library Association, 1989).

A working definition of health information literacy is “the set of abilities needed to: recognize a health information need; identify likely information sources and use them to retrieve relevant information; assess the quality of the information and its applicability to a specific situation; and analyze, understand, and use the information to make good health decisions” (MLA Net, 2003).

**What Is Known about Basic Adult Literacy?**

The National Adult Literacy Survey, conducted in 1992 and again in 2003, and the International Adult Literacy Survey, completed in 1994, gave North Americans and Europeans some startling news about the reading and writing abilities of those sixteen and over. Both surveys evaluated three types of literacy:
Prose literacy—the most common form of prose literacy used is the newspaper or magazine article.

Document literacy—the questionnaire required participants to read information in table form or in lists, such as a bus schedule or a table of contents.

Quantitative literacy—using a graph, chart, or performing an arithmetic operation, such as calculating a tip.

Within each type of literacy, five levels were defined, with level one being the lowest and five the highest. In both surveys, so few respondents scored at level five (about 3 percent for both Canada and the United States) (Clark, 1996) that the results were deemed statistically insignificant and the scores were combined with those at level four.

Those adults at the lowest levels of literacy (levels one and two) are of greatest concern for literacy advocates. Between 20 and 23 percent of Americans scored at the lowest level of prose, document, and quantitative literacy, while closer to 15 percent of Canadians fell into this category (Clark, 1996). The numbers increased for level two, with over 25 percent of both Americans and Canadians scoring at this level (Reading the Future, 1996). These two levels combined represent close to half the adult population.

**Where Does It End? Begin?**

Quite apart from the alarmingly low basic literacy rates in North America and Europe, health issues are notoriously complex and bewildering. The most educated person when confronting a major health crisis can have problems understanding the information presented. Emotional exhaustion, medication side effects, and general fatigue can all play a role in obscuring messages. In Quebec as elsewhere, issues of language confound comprehension every day. Problems navigating the health system exacerbate many problems. Cultural issues or lack of sensitivity to cultural issues can create problems of cooperation in health care and foster distrust and secrets between doctor and patient.

Much research is now being done on the impact of low literacy, language barriers, and cultural issues on health. Some studies focus on the cost of treatment, while others focus on the health outcomes associated with poor health communication. Cost analysis generally concludes that, while health outcomes may not be significantly different, those with low literacy require two to three times as many visits to understand the same information as those with excellent literacy skills. Other studies show that low literacy contributes to more hospitalizations, thus costing the health care system billions of dollars (Gordon, Hampson, Capell, & Madhok, 2002; Weiss & Palmer, 2004; Baker, Parker, Williams, Clark, & Nurss, 1997; Ad Hoc Committee, 1999).
Healthy People 2010 recognizes health communication as an important focus area and leading health indicator toward more effective preventative health initiatives:

Closing the gap in health literacy is an issue of fundamental fairness and equity and is essential to reduce health disparities. Public and private efforts need to occur in two areas: the development of appropriate written materials and improvement in skills of those persons with limited literacy. The knowledge exists to create effective, culturally and linguistically appropriate, plain language health communications. (U.S. Department of Health and Human Services, 2000, p. 15)

CASE STUDY: A NEUROLOGICAL DISORDER PATIENT RESOURCE CENTER

The Neuro-Patient Resource Centre began as an initiative of members of the Patient’s Committee of the Montreal Neurological Hospital, who saw a need for quality health information to be made available to all patients of the hospital. The mission and goals of the Resource Centre are as follows:

The mission of the Neuro-Patient Resource Centre is to provide health information in English and French to patients, their families and caregivers, and the general public. Our services are designed to help individuals become informed and active partners in their health care. Our goals are

To provide patients, their families, and caregivers with easy access to a source of reliable consumer health information
To create awareness among hospital staff regarding the health information needs of patients and their families
To advocate and promote the individual’s right to confidentiality and unrestricted access to medical and health information
To work in partnership with hospital staff to create patient education materials
To initiate and participate in research dealing with the impact of health information on human behaviour (Montreal Neurological Hospital, n.d. a).

This mission and goals are based on ideas put forward in the hospital’s Patient Services Steering Committee Report: “Individuals who are active in making decisions about their care generally do better than those who are not. For patients to take control of their health and well-being and make informed health care choices, they need both information and knowledge” (McGill University Health Centre, 1997).

Structure and History

The Resource Centre is an independent patient and family information library. It was conceived as an initiative of members of the Patients’ Committee, which is a government mandated patient advocacy group in
the hospital. Instead of positioning the Resource Centre under the auspices of either the Nursing Department or the Medical Library, where patient libraries are often positioned, it was decided that it should collaborate with, but be independent of, these groups. This decision was made because of concerns that, if it was organized under the Nursing Department, the focus would likely be more on patient education than information. Within the Medical Library, it was felt that doctors, nurses, students, and patients in the same library would not be the best way to serve the needs of these groups. The environment of the Resource Centre needed to be more family friendly than scholar friendly. Ultimately, due to space limitations, the Patients’ Committee moved in with the Resource Centre. This has been found to be an excellent partnership.

Use of the Resource Centre—Purpose

It did not take long, working within the context of a hospital, to begin to realize where the barriers preventing patient and family members’ “access to health information” lay and in how many ways the Resource Centre could ameliorate the situation.

It is common for patients to arrive at the door of the Resource Centre looking for information on a condition of which the library staff has never heard. As the Resource Centre is in a specialized hospital the staff know that very rare diseases are diagnosed and treated here, and it is entirely possible that the patient has a condition that is, in fact, new to everyone. More often than not, however, the patient has misheard the diagnosis or heard only incomplete information. This can be attributed partially to the stressfulness of the medical appointment itself. The appointment is often hurried and patients are reluctant to take up too much of the doctor’s time.

Sometimes the doctor has bad news to impart. Once a person has been told that they have a serious health problem like a brain tumor, cancer, or multiple sclerosis or a disorder with a name that is new to them, like chronic inflammatory demyelinating polyneuropathy or syringomyelia, it is very difficult to hear anything else. The patient can easily forget to ask necessary questions like, What kind of brain tumor? What is this disease and what is the treatment for it? In addition, a diagnosis can be just as shocking and difficult to understand to a family member as the patients themselves.

There is also the problem that the language or jargon of medicine is unfamiliar to most people regardless of their level of education. One would like to believe that doctors and nurses have become more sensitive to this and have adjusted their language accordingly when dealing with patients. Unfortunately, based on our experience, this is often not the case. A related difficulty that people have in understanding what the doctor is saying is that many people do not know very much about anatomy and physiology. When the doctor says “you have a lesion in your occipital lobe” or “we are
going to place this tube down to your duodenum," the patient may not know where on the body these parts are located.

Even before a diagnosis is given there are major communication problems between the health care professional and the patient. People are told they are scheduled for diagnostic tests and will undergo examinations that they do not really understand. What exactly is an MRI or a lumbar puncture? Why does the doctor want to see me walk as part of a neurological exam? Often a doctor will not stop and explain. Sometimes a patient is too shy to ask or does not think of asking these questions until after the appointment is over.

After a diagnosis is made or after the medical team has determined an inability to make a comprehensive diagnosis, there may be a discussion of treatment options. Usually the patient comes to this appointment armed with nothing. Sometimes the doctor may have made a decision on the best treatment and may present this to the patient without discussing the rationale. The pros and cons of other treatment options may not be presented at all. Side effects may or may not be discussed. The level of pain involved, for example, may not be brought up.

The result of these stresses and omissions is that crucial information is never given or, if it is given, it often gets lost. The health professional may believe that the information has been given and frequently is not sensitive to the fact that the communication is not complete. Although the information may have been presented, it has not been received. These common scenarios provide many opportunities for the Patient Resource Centre to participate in patient care by providing information that educates and empowers patients and their families.

From first contact, the Resource Centre may be involved with the patient. Many telephone calls and e-mails are received requesting information on how to get an appointment at the hospital. The Resource Centre provides the names and contact information of specialists and clinics that focus on specific disorders. The Resource Centre can provide information on whether or not a specific treatment or surgical operation is performed at the hospital.

Another point of first contact with patients is online. The Resource Centre maintains a Web site that includes information about the Resource Centre, about diagnostic tests, about some disorders and procedures, and about clinics at the hospital (Montreal Neurological Hospital, n.d. b). The Resource Centre provides links to quality Web sites both on neurological subjects and to more general health search engines, as well as links to information on evaluating health information. Judging by the calls and e-mails received by the Resource Centre, this is the first contact many patients have with the hospital.
The Collection—Scope

The goals of improving health literacy and health information literacy inform almost all the activities of and services provided by the Neuro-Patient Resource Centre. The Resource Centre maintains an up-to-date bilingual (French and English) collection of monographs written in plain language on neurological and psychiatric disorders, as well as books on coping with chronic illness, pain, and death for adults and children. The Resource Centre also has reference books on general anatomy, neuro-anatomy, and physiology; medical dictionaries and encyclopedias; and guides to medical tests, as well as neurology textbooks.

The Resource Centre buys, or is given for distribution, pamphlets, information sheets, and booklets for patients on neurological disorders and related health promotion topics. The staff of the Resource Centre considers these “give-aways” extremely valuable. They usually come from very authoritative, unbiased sources like national organizations for a particular disorder. They are almost invariably written in plain language (although with varying degrees of difficulty in the vocabulary), and sometimes are available in more than one language. The fact that the patient or family member can take the information home with them means they can read it over and over again and they can show it to other members of the family; if they have trouble with the language the patient can get help with it. They can bring it with them to their medical appointments to discuss with the doctor and nurse, and they do not need to know how to use a computer to get it.

As discussed in the MLA satellite conference Reading Between the Lines (2003), it is difficult to tell, just by a request, the level of material a patron will need. While some tips were offered, excellent comments were made by Michele Spatz, who emphasized that the needs of the largest number of patrons can be met by offering materials with a wide range of difficulty. The collection philosophy at the Resource Centre is that the collection seeks to achieve equal amounts of information in French and English. The bulk of the collection needs to be written in plain language, that is, words in common usage, with some references in technical language and some simplified materials that are easy to read. Dictionaries and encyclopedias are other crucial tools in deciphering medical information.

For more in-depth medical research the Resource Centre uses its affiliation with McGill University for electronic journal access, and the Resource Centre maintains a very close relationship with the hospital’s medical library staff downstairs. The librarian at the Resource Centre will conduct a literature search for the patient and provide copies of journal articles for personal use only. The Medical Library provides an interlibrary loan service for a small fee that is paid by the Resource Centre. If a patient wants to do his/her own research in the library, he/she is welcome to use the collection of the Medical Library on a consultation basis only.
Reference service is by phone, in person, and by e-mail. Consultations are made by patients and the general public in French and English from all over the world. Nurses from other hospitals call the Resource Centre to get patient information and community referrals.

Other McGill University Health Centre librarians call the Resource Centre for information and vice versa. Since not all information requests are neurology or neurosurgery related, the patient can easily be referred to another McGill University Heath Centre library better equipped to handle his/her particular information need.

As a library, the Neuro-Patient Resource Centre aims to provide resources to all types of patients and families. This is a continual challenge. The issue of language is a particularly acute one for the Resource Centre. The information available, in all formats, is overwhelmingly English. About one half of the user population is French speaking, and many of these patients and family members do not read English well enough to understand most health information—even if it is written in plain language. Some Canadian organizations and Web sites have information in both languages, but these are very few. European resources can be helpful, but there can be differences in the way medicine is practiced in Europe; anyone using information from other countries needs to understand the potential for these differences. The biggest obstacle is finding authoritative plain language material in French that is for a Quebec audience, not a European one.

When information in English or Spanish is needed, there is a great deal of patient information being made available, by very reliable sources, in the United States. However, there are some differences in the practice of medicine between Canada and the United States. A striking example is in medications: Canada and the United States often have different commercial names for the same drug; a medication may be approved for use in one country but not in the other, or it may have different indications for use.

**Literacy and Health Information Literacy**

The issues of literacy and health information literacy cut across a broad spectrum of patrons. At the Resource Centre there have been patrons who are very highly educated but simply lack the skills in the medical arena to find the information they need. In that case the Resource Centre helps them by providing more technical information and by providing training on the use of medical databases.

The Resource Centre participates in events that are organized by different groups in the hospital to promote awareness of health issues or to provide information about specific disorders such as stroke awareness days, epilepsy information days, and public lectures given by our doctors and researchers. The Resource Centre maintains patient information bulletin boards all over the hospital. These outreach efforts are particularly
important. People do not expect to find a patient resource center in the hospital. That is why at the front door there is a large bulletin board full of information for patients and their families with a big welcome from the Neuro-Patient Resource Centre.

**Authority**

Authority of health information is critical in the environment of the Resource Centre. Numerous times the staff has experienced desperate people coming for information on unproven medications and treatments as well as doctors and clinics who practice a form of medicine that is not based on scientific evidence. The staff researches these practitioners and treatments and explains why the legitimate medical community would not endorse them.

There is also much “patient information” being produced by pharmaceutical companies that is really nothing more than thinly veiled advertising for one medication or another. The staff of the Resource Centre is vigilant in weeding out these marketing tools from its collection and making every effort to reduce its presence in the hospital.

The staff of the Resource Centre strives to keep an open dialogue with hospital staff; when the Resource Centre receives new materials on a topic, say, metastatic brain tumors, the members of the brain tumor team are informed that this material has arrived. Recently a publication on amyotrophic lateral sclerosis in Chinese was put into the collection, and the members of the ALS team were immediately informed. The result of these efforts is that many of the health professionals at the hospital refer their patients to the Resource Centre. In turn the Resource Centre welcomes suggestions from the health care staff for additions to the collection.

**Currency**

A critical concept in health information is that of currency. The field of medicine is a rapidly advancing one. A good example is treatment for multiple sclerosis. It used to be that there was nothing that could be done. When a patient was diagnosed with multiple sclerosis there was no proven treatment. Over the past few years studies have shown that, if certain disease modifying medications are initiated early, they can slow the progression of the disease over time. If a newly diagnosed patient is having a number of attacks per year, it will now be recommended that they follow a course of medications even though they may not be experiencing disability. This is an area of active research. For patients who have a condition called benign multiple sclerosis, there is an 80 percent chance that it will develop into a more progressive type of multiple sclerosis in the long term (about fifteen years). Under investigation is whether it is useful to give medication to these patients. There is also recent proof that certain types of chemotherapy,
which had been used only for cancer patients, can reduce the number of attacks experienced by patients with certain types of multiple sclerosis. These therapies can have serious side effects, and patients who are deciding whether or not to take them need the best, most current information.

In addition, the hospital staff needs to know that when a patient has questions about his/her treatment they can send the patient to the Resource Centre for current, authoritative information. This has been one of the most important steps in establishing the Resource Centre as part of the health care team. It has also motivated a number of doctors and nurses to make donations of quality materials to the Resource Centre.

**Production of Materials—Audience Driven**

One of the most important ways that the Resource Centre collaborates with the health professionals in the hospital is through our program of producing patient education and information materials. For example, information on diagnostic tests, clinic handbooks, caregiver guides, and fact sheets on specific disorders and procedures have all been produced collaboratively with the Resource Centre. All of these projects require the involvement of doctors and advanced practice nurses. Sometimes the Resource Centre collaborates with physical, occupational, and speech therapists; social workers; and technicians. Part of the Resource Centre contribution to these publications is to edit the information and, when needed, change the language to something that can be understood by people who do not have a medical vocabulary. All publications are produced in both English and French. After editing is completed, two patients (without a university education) are recruited and asked to review the text. Resource Centre staff work with a graphic designer to make the information visually interesting and inviting. All the patient information produced follows plain language guidelines, which include using the active voice, writing directly to the reader, using common words rather than technical jargon, and using short words and sentences. The materials are monitored for reading level, usually no more than grade eight. The Resource Centre has recently begun producing easy-to-read versions of some of these materials to reach people who may have difficulty reading in English or French. The challenge is that it can be difficult to translate complex concepts into very simple words. Using pictures can often help explain a procedure more clearly than words. Clear graphic design can also help people penetrate a “wall of words.”

The response of the hospital staff to Resource Centre productions has been overwhelmingly positive. This, perhaps more than anything else, has influenced the Resource Centre’s acceptance as part of the patient care team and has highlighted the need for better communication with patients by all members of the team as well as providing some strategies for achieving this.
What Role Do Libraries Have?

Libraries are recognized for their firm belief in the right to access information, and this naturally extends to the right to access and understand treatment and disease information. Libraries are often perceived as neutral territory and a welcoming environment for community members. Public libraries play important roles in basic literacy training and provide space for local organizations to meet and exchange ideas.

However, people with low literacy skills are not necessarily the same people who come into the library. Despite our belief that libraries are nonjudgmental places, open to everyone, many people may find libraries intimidating and never come to us for the information they need. Public libraries are alive and well in Sweden. In the report Catching up with the Swedes, Kapsalis (2001) shows a correlation between library usage and literacy rates. Unemployed Canadians rarely use public libraries, with only 23 percent stating they used libraries at least monthly, compared to 33 percent of Swedes. About half of Canadian youth use libraries, compared to 81 percent of youth in Sweden (Kapsalis, 2001).

As illustrated above, the library can provide multiple functions within a broad context: welcome desk, information provider, information producer, referral agent, and authority controller. These efforts can only be successful through partnerships with nonlibrarians and librarians alike. As discussed elsewhere in this volume, librarians increasingly need to leave the confines of their library buildings in order to reach the wider community. If not everyone considers the library a place for learning and information, then we need to expand our reach through a variety of partnerships.

We encourage every librarian, regardless of setting, to develop a good working relationship with a medical librarian. Health issues affect almost everyone over the course of a lifetime. Knowing someone you can turn to for document delivery, a good referral, and a specialized list of resources can be invaluable. With the right partnerships, our role as literacy brokers can span the wide range of basic adult literacy to health literacy, and using the principles of information literacy we can develop the concept of health information literacy.

References


Access to Electronic Health Information for the Public: Analysis of Fifty-Three Funded Projects

ANGELA B. RUFFIN, KEITH COGDILL, LALITHA KUTTY, AND MICHELLE HUDSON-OCHILLO

ABSTRACT
In 2000 the National Library of Medicine (NLM), a component of the National Institutes of Health, funded fifty-three consumer health outreach projects through the National Network of Libraries of Medicine (NN/LM). The goal of all projects was to improve access to electronic health information for consumers. Drawing on experience gained in the NN/LM public library pilot projects undertaken in 1998–1999, the projects involved medical and public libraries in partnership with a wide range of community organizations, including public health departments, schools, churches, and local professional associations. The projects provided training in the use of MedlinePlus and other health information resources and support for Internet access in a variety of settings. The projects used an array of approaches over an eighteen-month funding period. This article presents descriptive information about the projects, highlights common barriers, and provides an analysis of the effectiveness of methods and approaches used.

INTRODUCTION
There has been considerable research on the nature of consumer health information (CHI) and the frequency of needs for it. Reflecting on this research, Deering and Harris (1996) note that CHI encompasses patient

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information, which includes medical instructions and decision support information, as well as health education, self-care information, “quality-in-care information,” and alternative medicine. Reviewing previous studies of the demand for CHI, Deering and Harris conclude that CHI requests account for a substantial portion of reference questions raised in public libraries. They suggest that as many as fifty-two million health-related requests are raised in public libraries every year.

Since Deering and Harris’s review much attention has focused on CHI available from Internet-based resources. Based on a survey conducted in 2001, Harris Interactive (Taylor, 2001) estimates that 100 million adults in the United States consult online sources for health information. This figure represents three-quarters of adults who use online resources and approximately 47 percent of adults in the United States. Among adults who seek health information online, the average frequency is slightly more than three times per month.

Pifalo, Hollander, Henderson, DeSalvo, and Gill (1997) studied the impact of a CHI service on individuals. Surveying users of a CHI service provided by the Delaware Academy of Medicine, Pifalo and her colleagues found cognitive, affective, and behavioral impacts. The majority of respondents (94 percent) reported that they learned more about an illness or health issue. Slightly more than half (52.1 percent) reported that the information reduced anxiety. Approximately half (51.3 percent) indicated that the information led them to address questions to their health care providers.

Information about the motivations associated with seeking CHI online emerged from a random survey conducted in 2003 of users of MedlinePlus, a leading Web-based source of consumer health information. Results of this survey indicate that the most common reason for visiting the site was to find information on a specific condition (62 percent). The next most common reason for visiting MedlinePlus, to find information about a specific medication, was selected by 29 percent of survey respondents (Backus, 2003).

Libraries have developed a wide array of CHI resources, collections, and services, but Rees (1982) summarizes the essential role of libraries as coordinators of access to health information: “The role of the library has begun to emerge with some clarity. Increasingly, the library (public and hospital) is called on to coordinate health information access at a local level, utilizing the many information and educational resources available locally, regionally, and nationally” (pp. 37–38).

Interest in coordinated access to health information is evident in the collaborations of the earliest libraries in the United States. In a study of health-related collections in public libraries, Wannarka (1968) reports that Boston Public Library held the earliest such collection. Primarily the result of physicians’ gifts, this collection totaled 28,604 volumes in 1864, exceeding
the Boston Medical Library’s collection of 20,285. In 1904 Boston Public Library transferred 21,000 volumes to the Boston Medical Library, which merged with Harvard’s Medical Library in 1965 to form the Francis A. Countway Library of Medicine. Wannarka notes that the 21,000 volumes originally transferred in 1904 remain the property of Boston Public Library.

A series of papers presented fifty years ago at the annual meeting of the Medical Library Association explored issues emerging from CHI services provided by health sciences libraries. Later published in the *Bulletin of the Medical Library Association*, these papers consider policies related to collection access for members of the general public as well as opportunities for collaborations with public libraries. Representing the Armed Forces Medical Library, Jacqueline Chambers (1955) notes that “It is important that public and medical libraries cooperate with one another wherever this is feasible, and it is to their mutual advantage to divide the responsibilities which should be met” (p. 260).

Collaborations between public and health sciences libraries were features of a handful of projects funded by Library Services and Construction Act (LSCA) Title I grants in the late 1970s (Hollander, 1996). Among these was the Consumer Health Information Network (CHIN) project in Cambridge, Massachusetts. A collaboration of Mount Auburn Hospital and six public libraries in the surrounding community, the CHIN project provided for training of public library staff, cooperative collection development, interlibrary loans, and reference assistance (Gartenfeld, 1978).

Health sciences libraries also have collaborated successfully with community-based organizations in addition to public libraries to promote access to health information. Sligo and Jameson (2000) underscore the importance of community engagement for the successful dissemination of health information. In their report of a study of Pacific islanders’ participation in cervical screening services, Sligo and Jameson note that this population “strongly favored sources of information that were mediated through their community groups” (p. 858). Community assessment and community engagement are also central ideas in Burroughs’s *Measuring the Difference* (2000), a manual guiding the planning and evaluation of health information outreach projects.

Community engagement is a guiding theme in a number of projects sponsored by the National Library of Medicine (NLM). A project targeting Native American and Alaska Native communities is known as the Tribal Connections project. Coordinated by the University of Washington, this initiative has resulted in improvements in Internet connectivity in sixteen communities. Community assessments and participation were key to the success of this effort (Wood et al., 2003). Another NLM-sponsored project conducted by George Washington University has resulted in collaborations with a consortium of nonprofit clinics in the District of Columbia. Interven-
tions at each clinic are determined by the needs of that clinic’s staff and patients (Partners for Health Information, 2001).

Other collaborations between health sciences libraries and community-based organizations have led to a number of practical findings. With partial support from the National Library of Medicine, the University of Illinois at Chicago’s Library of the Health Sciences collaborated with a variety of community-based organizations to extend access to HIV/AIDS information. In their report of the project Martin, McDaniels, Crespo, and Lanier (1997) note the importance of identifying community representatives who can serve as liaisons between the targeted community and the library. They also note the value of the library’s repeated contacts and communications with the targeted community.

Also with support from the National Library of Medicine, a subsequent project conducted by the University of Illinois at Chicago focused on reducing asthma and lead poisoning among children through improved access to environmental health information resources. This project entailed collaborations with seven community-based organizations: two public schools, three community action groups, and two public health organizations. In her report of the project, Scherrer (2002) highlights the need for community assessments when planning interventions as well as a theoretical framework to inform the planning and evaluation of the project. Scherrer also notes significant cultural differences between academic health sciences centers and community-based organizations, and she underscores the importance of cultural competence among project staff.

A host of public health projects have relied on community partnerships and collaborative efforts. Notable among these is the Turning Point initiative. Funded by the Robert Wood Johnson Foundation and the W. K. Kellogg Foundation, the Turning Point initiative seeks to improve the public health system in the United States by making it more community-based and collaborative. Since its inception in 1997, Turning Point has resulted in 23 state and 41 community-level partnerships aimed at improving public health through community collaborations (Turning Point National Program Office, 2003).

Collaborations such as those fostered by the Turning Point initiative bring together institutions seeking to realize a common goal that may not be attained separately. In a report of their efforts to develop a collaboration to promote breast cancer education among rural and Hispanic migrant and seasonal farmworker women, Meade and Calvo (2001) summarize a wide array of previous community-academic coalitions targeting specific health concerns. Community-academic collaborations are also a hallmark of the urban research centers funded by the Centers for Disease Control and Prevention since 1995 (Metzler et al., 2003) and have led to a growing body of research known as community-based participatory research.
At the New York Academy of Medicine’s Center for the Advancement of Collaborative Strategies in Health, Lasker and Weiss (2003) have framed a model for community partnerships and collaboration. Lasker and Weiss observe that public health concerns often “cannot be solved by any person, organization, or sector working alone” (p. 15) and propose a model of community-level problem solving that relies on empowering individuals, bridging social ties, and creating synergy among diverse participants. Green and Kreuter (1999) have also explored the ideas of social capital and community coalitions to address public health concerns, noting the complexities of power sharing among coalition participants.

NLM’s efforts at improving access to health information have been informed by the related work of other libraries and public health organizations, only a fraction of which is represented in the previous summary. NLM has a long history of providing health care professionals with timely, up-to-date information. A vigorous outreach effort to health care professionals began with the 1989 NLM Board of Regents special panel report, Improving Health Professionals’ Access to Information. The report encouraged NLM to develop an outreach program to reach health professionals who did not have easy access to recent scientific and biomedical information. It also noted the importance of the National Network of Libraries of Medicine (NN/LM) in helping NLM reach health professionals throughout the United States and making them aware of the resources and services available from the NLM and the NN/LM. In the five years following the Board of Regents’ report, NLM sponsored approximately 300 outreach projects targeting health professionals. These projects engaged more than 500 institutions, often in close collaboration with NN/LM network members (Wallingford et al., 1996).

With the introduction of free MEDLINE searching on the Internet through PubMed in 1997, a new wave of users began to access NLM’s database. The increased interest in MEDLINE searching by the general public led to the development of MedlinePlus and provided the impetus for NLM’s consumer health focus to provide health information for the public. The NN/LM and its network members were again key to NLM’s efforts to improve access to information, now for the general public as well as health professionals. In 1998 NLM began to explore ways to reach consumers through collaborations with public libraries and to foster partnerships between NN/LM network members and public libraries (Wood et al., 2000). From the beginning of this initiative, there was clear recognition that hospital, academic health sciences, and public libraries are important partners in reaching the public.

NLM has recognized the importance of supporting library and community partnerships in order to reach the public. In an effort to encourage and enhance community partnership building, NLM issued a request
for proposals from NN/LM network members in April 1999. The request was for projects that would focus on improving electronic access to health information for a variety of groups, including consumers, underserved and minority populations, public health workers, public libraries, and community-based and faith-based organizations. Up to $10,000 was available for each project being conducted by a single institution, and up to $40,000 was available for projects that entailed formal institutional collaborations. The request for proposals encouraged collaborations among NN/LM member libraries and public, state, and school libraries as well as health information resource centers and community- and faith-based organizations.

Proposals were received in July 1999 and were reviewed by multiple panels of reviewers representing health sciences libraries, health care professionals, public health workers, public libraries, state libraries, and community- and faith-based organizations. Fifty-three projects were funded. Figure 1 is a map representing the geographic distribution of the projects in thirty-four states and the District of Columbia. All projects were administered as subcontracts through the NN/LM Regional Medical Libraries and were implemented over an eighteen-month period.

![Figure 1. Map of Projects.](image)
Methods

The authors relied on the quarterly and final reports of the projects as well as interviews with project directors to gain an understanding of the projects. Interviews with project directors were conducted between October 2002 and January 2003. The semi-structured telephone interviews were guided by a set of questions that addressed project activities, target populations, approaches taken, methods of publicity, the project’s impacts on the target populations, and lessons learned. The interviews also provided an opportunity to verify summary information obtained from each project’s reports.

The authors used NVivo software from QSR International to analyze the interview data. NVivo provided a system for coding, linking, searching, and organizing the qualitative information obtained during the interviews. A taxonomy was developed to identify categories for coding the interview documents in NVivo. This taxonomy was based on the prominent and recurring themes that emerged from a review of the data.

Findings

Eleven single institutions received funding up to $10,000, and forty-two multitype projects received support of up to $40,000. Among the forty-two projects that entailed institutional collaborations, the most frequent partnerships were among academic health sciences libraries, public libraries, hospital libraries, and community-based organizations. Although many projects relied on collaborations spanning more than two types of organizations, the following list identifies the most common institutional partnerships formed as a result of the projects:

- 18 academic health sciences library–public library partnerships
- 16 hospital library–public library partnerships
- 9 academic health sciences library–community-based organization partnerships
- 8 hospital library–community-based organization partnerships
- 4 academic health sciences library–hospital library partnerships

Target Populations

Many projects targeted multiple populations in their efforts to improve access to electronic consumer health information. Thirty-eight projects worked directly with members of the general public, often targeting specific populations such as racial and ethnic minorities (9 projects) and seniors (7 projects). Projects also targeted a variety of professional populations, including public librarians (29 projects) and health professionals (13 projects). Projects targeting health professionals typically aimed to increase health professionals’ awareness of resources available to support patient education.
Training

Forty-five of the fifty-three projects included training as part of the intervention. Approximately 820 training sessions were conducted across these forty-five projects, reaching an estimated 13,750 individuals. Almost all the projects that included a train-the-trainer approach highlighted the success of this approach. However, one project noted a lack of success with this approach in preparing members of support groups as trainers. In their reports and interviews, project directors emphasized the value of personal contact, site visits, and “putting a face to a name” as contributors to the success of their training and outreach efforts. In their reports and interviews, project directors pointed to a variety of other factors influencing the success of the training, including the scheduling and location of the training sessions, the materials used to support the training, and an accurate assessment of participants’ computer skills.

Several project directors who provided training in public library branches and made accommodations for hands-on practice with the resources observed that these approaches were particularly effective. They also noted the importance of flexibility in the scheduling of training events and training locations. Most projects underscored the value of providing training in small-group settings in participants’ own environments. Other project directors suggested, however, that participants who were trained in their own work settings were more likely to be distracted by work-related responsibilities.

Many projects discovered the importance of pretesting all translated materials and customizing the content to the needs and interests of the targeted community. This was found to be particularly useful when training specific populations. Issues related to cultural competence were particularly significant for projects that targeted non-English-speaking communities. A project targeting the hearing impaired reported that there are many medical terms for which signs are not available in American Sign Language.

Project directors discovered significant variability in trainees’ computer skills, and one noted that self-reported data about computer proficiency may not be reliable. Other methods may be needed for ensuring that participants in a session are at a common level of proficiency. For members of a targeted community with limited computer proficiency, it may be necessary to provide training on basic computer skills as a foundation for training on computer-based health information resources.

Web Site Development

The development of Web sites and pages was a major component of thirty-eight projects. Among these projects, several added new Web pages to their organization’s existing Web site. Project directors with dedicated information technology (IT) staff reported that this was advantageous for the development of the project’s Web presence. Multiple project direc-
tors commented on the value of having staff with varied experience to help develop and create the project’s Web presence. Project directors also underscored the benefit of identifying a single staff member with primary responsibility for technical difficulties.

As part of the development of a project’s Web presence, directors noted the value of ensuring the availability of usage statistics. They also highlighted the value of a simple, streamlined design to enhance a site’s usability. Collaborations in developing information for the project’s Web presence were noted as particularly helpful. Projects that undertook usability testing reported the benefit of this effort in the site’s development.

Publicity and Marketing

All projects were aware of the importance of promoting their program. More than half of the projects developed and distributed project-specific promotional materials. These products included bookmarks, information prescription pads, flyers, posters, displays, videos, and screen sweeps. Promotion through newspapers and newsletters was also popular. Participation in health fairs and exhibits was effective in thirteen projects, and “word of mouth” was considered effective in twelve projects. Word of mouth included communications by phone, staff contacts, personal contacts, and at meetings. Other methods included the use of Web sites, listservs, e-mail, intranet pages, links on local Web sites to the organization’s Web site, and announcements in professional journals. Most projects employed more than one marketing approach.

Project Evaluation


1. Identify the target community and conduct a community assessment
2. Establish goals and objectives
3. Develop activities and strategies based on audience assessments
4. Establish evaluation objectives and develop methods of data collection
5. Carry out planned outreach and evaluation activities
6. Disseminate results of the evaluation

The fifty-three projects implemented a variety of approaches to evaluation, many of which correspond to components of the six-stage framework presented in *Measuring the Difference*. It should be noted that most of the fifty-three projects funded as part of the Access to Electronic Health Information for the Public program were planned prior to the widespread distribution of *Measuring the Difference*. Two project directors reported that they did not undertake a structured approach to evaluation but relied instead on informal methods and unsystematically gathered anecdotal evi-
evidence of the project’s impact. Three projects conducted a structured needs assessment in tandem with their outreach activities. Many project leaders conducted some form of community assessment prior to the project as part of developing the project’s funding proposal.

Surveys and measures of use were the most common strategies employed in the fifty-one projects that undertook a systematic approach to evaluation. Written surveys were administered as part of training sessions in thirty-six projects. These included training session evaluation or satisfaction surveys (thirty projects) and pre- and post-tests of participants’ knowledge (thirteen projects). Some projects administered pre- and post-tests of participants’ knowledge as well as training evaluation surveys.

Other projects surveyed participants through questionnaires and interviews to assess the project’s impact. In nineteen projects, questionnaires were administered to participants at a time apart from a training event. Six projects that developed Web sites gathered evaluation data through an online feedback survey. Five projects surveyed participants through in-person or telephone interviews to gather evaluation data.

Web site usage statistics were gathered in ten of the thirty-eight projects that developed a Web resource. Two projects monitored the frequency of health-related questions at a library’s reference desk, and one project measured patients’ use of a hospital library.

Less frequently used methods of evaluation data collection included focus groups (two projects) and reviews of Web sites by content experts (two projects). Five projects also systematically gathered qualitative data, primarily anecdotes related to project impacts. Although the long-term impacts of outreach in a community may be difficult to ascertain, one project pointed to the establishment of a new branch library in the county hospital as an indicator of the project’s success.

Measuring the Difference

Measuring the Difference differentiates formative evaluation, in which findings are used to refine ongoing outreach activities, from summative evaluation. While other projects may have used evaluation data to modify their outreach activities, two project directors explicitly noted in their final reports or follow-up interviews that evaluation findings were used to refine ongoing outreach activities. Both of these projects relied on data gathered from training session evaluation questionnaires for their formative evaluations.

Project evaluation may also consider whether outreach activities are sustained beyond the period of time for which external funding is available. Reflecting on the sustainability of activities, Rees (1982) observed a common pattern among CHI projects:

There would appear to be a sequence of events in the development of structured CHI programs. Under the initial impetus provided by one
or more persons, funding is secured from local, state, and/or federal sources for the initiation of the program. After successful promotion, demonstration, and marketing, the program is absorbed into regular library operations as a result of the buildup of expectations, resources, and expertise. In this manner, successful CHI programs “self-destruct” as they become part of the parent library system. The desired objective of funded CHI programs is, therefore, to catalyze, develop, extend, demonstrate, evaluate, and refine innovative services that will then be integrated into regular library operations (p. 38).

When interviewed, the majority of project directors indicated that project activities had continued beyond the period of funding. Ongoing activities typically include training and promotion of MedlinePlus and the project’s Web site. Many of these activities are being conducted through an ongoing collaboration with other organizations. Thirty of the thirty-eight Web sites developed as part of the projects were still available at the time the interviews with project directors were conducted. Project directors responsible for twenty-one of these sites reported that they were being updated on a frequent basis.

**Key Lessons Learned**

The interviews with project directors provided an opportunity for them to highlight significant lessons learned during the course of their projects. The themes that emerged related to partnerships, leadership, commitment, communication, and decision making.

Involving the targeted community in planning and designing activities increases each group’s investment in the project. For collaborative partnerships to be successful, it is essential to collaborate with representatives who are familiar with their organizations’ constituents. Consulting with others who have collaborated with similar groups may provide useful information during the planning of a project. Including members of the target population with diverse expertise in an advisory role for planning and needs assessments can serve as not only a strategic function but as an information portal. Those projects focusing on Hispanic populations found that having Hispanic community leaders involved in the project from inception, in pretesting materials for cultural and medical appropriateness and in providing feedback, was extremely valuable to the success of the project.

Successful partnerships require an evaluation of potential partners’ resources, including staff and time availability. Interest and enthusiasm, especially among an organization’s leaders, are also key attributes to consider among potential partners. One project focusing on training of library staff found that the most effective strategy in implementing the project was to have the support of the library’s administrators. Having administrators require participation among the staff proved to be a successful strategy for another project.
<table>
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<tr>
<th>Lead Institution</th>
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<th>Collaborations Resulting from Project</th>
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</tr>
<tr>
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<td>DC</td>
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<td>AHSL/Community Health Centers</td>
<td>Urban Clinics, Minorities, Hispanics, HIV/AIDS Patients, Uninsured Individuals</td>
</tr>
<tr>
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<td>Single</td>
<td>HL/PL</td>
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<td>PL/CBO</td>
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<td>AHSL</td>
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<td>AHSL/PL/CBO</td>
<td>African Americans, Urban Clinics, Minority Populations, Hispanics, HIV/AIDS Patients, Uninsured Individuals</td>
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<td>Public Librarians, Consumers</td>
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<td>State</td>
<td>Lead Institution Type</td>
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<td>Collaborations Resulting from Project</td>
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</tr>
<tr>
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<td>IL</td>
<td>AHSL</td>
<td>Multiple</td>
<td>AHSL/CBO</td>
<td>HIV/AIDS Patients, Inner-City Residents, Low-Literacy Individuals, Hispanics</td>
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<td>MD</td>
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<td>University of Massachusetts Medical School, Lamar Soutter Library</td>
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<td>Consumers Clinicians, School Nurses, Community Outreach Workers, Health Educators, Public Librarians, School Librarians</td>
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<td>Massachusetts General Hospital, Treadwell Library</td>
<td>MA</td>
<td>Hospital Library</td>
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<td>HL/CBO/PHD</td>
<td>Public Librarians, Youth at Boys’ and Girls’ Clubs</td>
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<td>Holland Community Hospital</td>
<td>MI</td>
<td>Hospital Library</td>
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<td>HL/PL/CBO</td>
<td>Health Care Professionals, Patients</td>
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<td>Mid-Missouri AHEC</td>
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<td>Public Librarians, Consumers</td>
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<td>Truman Medical Center East</td>
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<td>Hospital Library</td>
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<td>ICON: Omaha Area Health Information Consortium</td>
<td>NE</td>
<td>Library Consortium</td>
<td>Multiple</td>
<td>AHSL/Library Consortium/Medical Society</td>
<td>Public Librarians, Consumers, Seniors, Hispanics</td>
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<tr>
<td>Las Vegas Clark County Library District</td>
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<td>PL/SL/Academic library/Special library</td>
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<td>Lead Institution Type</td>
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<td>Collaborations Resulting from Project</td>
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<td>Multiple</td>
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<td>HL</td>
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<td>HL/CBO</td>
<td>Consumers, Public Librarians</td>
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<tr>
<td>SUNY Health Science Center at Syracuse</td>
<td>NY</td>
<td>AHSC</td>
<td>Multiple</td>
<td>AHSL/CBO</td>
<td>Seniors</td>
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<td>South Central Regional Library Council</td>
<td>NY</td>
<td>Library Consortium</td>
<td>Multiple</td>
<td>Library Consortium/HL/PL</td>
<td>Public Librarians, Hospital Librarians</td>
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<tr>
<td>Samaritan Medical Center</td>
<td>NY</td>
<td>Hospital Library</td>
<td>Single</td>
<td>HL/PL/CBO/County Social Service Agency</td>
<td>Public Librarians, School Librarians, Consumers</td>
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<tr>
<td>University of North Carolina, Chapel Hill, Health Sciences Library</td>
<td>NC</td>
<td>AHSL</td>
<td>Multiple</td>
<td>AHSL/PL</td>
<td>Consumers, Librarians, Public Health Workers</td>
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<td>Mountain AHEC</td>
<td>NC</td>
<td>AHEC</td>
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<td>AHEC/PL/CBO</td>
<td>Public Librarians, Community Coalition Coordinators, Health Educators, Public Health Nurses</td>
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<tr>
<td>Oregon Health Sciences University</td>
<td>OR</td>
<td>AHSL</td>
<td>Multiple</td>
<td>AHSL/Public Schools</td>
<td>School Nurses</td>
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<td>University of Pittsburgh, Falk Library of the Health Sciences</td>
<td>PA</td>
<td>AHSL</td>
<td>Multiple</td>
<td>AHSL/PL</td>
<td>Librarians, School Nurses, Students, Faculty</td>
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<td>Lead Institution</td>
<td>State</td>
<td>Lead Institution Type(^1)</td>
<td>Project Leadership: Single or Multiple Institution</td>
<td>Collaborations Resulting from Project(^1)</td>
<td>Specified Target Populations</td>
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<td>SC</td>
<td>AHSL</td>
<td>Multiple</td>
<td>AHSL/PL/SL</td>
<td>Minorities, African Americans, Inner-City Residents, Rural Residents, Low-Income Individuals</td>
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<tr>
<td>Rapid City Regional Hospital Health Sciences Library</td>
<td>SD</td>
<td>Hospital Library</td>
<td>Multiple</td>
<td>HL/PL</td>
<td>Public Librarians</td>
</tr>
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<td>University of Texas Health Science Center at San Antonio</td>
<td>TX</td>
<td>AHSL</td>
<td>Multiple</td>
<td>AHSL/PL/HL/CBO/AHEC/PHD</td>
<td>Librarians, Consumers, Health Professionals</td>
</tr>
<tr>
<td>University of Utah, Eccles Health Science Library</td>
<td>UT</td>
<td>AHSL</td>
<td>Multiple</td>
<td>AHSL/PL/CBO/AHEC/PHD</td>
<td>Hispanics</td>
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<td>Mary Washington Hospital, Medical Library</td>
<td>VA</td>
<td>Hospital Library</td>
<td>Multiple</td>
<td>HL/PL</td>
<td>Public Librarians, Other Librarians</td>
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<td>Public Health, Seattle and King County</td>
<td>WA</td>
<td>Public Health Department Hospital Library</td>
<td>Single</td>
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<td>Lesbians, Gay Men, Transgendered Persons</td>
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<tr>
<td>Yakima Valley Memorial Hospital</td>
<td>WA</td>
<td>Hospital Library</td>
<td>Multiple</td>
<td>HL/PL/CBO/PHD</td>
<td>Consumers, Health Professionals, Hispanics</td>
</tr>
<tr>
<td>University of Wisconsin, Madison</td>
<td>WI</td>
<td>AHSL</td>
<td>Multiple</td>
<td>AHSL/PL/State Library</td>
<td>Public Librarians</td>
</tr>
<tr>
<td>Medical College of Wisconsin</td>
<td>WI</td>
<td>AHSL</td>
<td>Multiple</td>
<td>AHSL/PL/HL</td>
<td>Consumers</td>
</tr>
<tr>
<td>Wyoming Medical Center</td>
<td>WY</td>
<td>Hospital Library</td>
<td>Multiple</td>
<td>HL/PL/PHD</td>
<td>Librarians, Health Department Staff</td>
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</table>

\(^1\)Institution types are abbreviated as follows: AHEC: Area health education center; AHSL: Academic health sciences library; CBO: Community-based organization; HL: Hospital library; PHD: Public health department; PL: Public library; SL: School library; N/A: Not applicable—no collaboration undertaken as part of project
Potential project partners should also be able to devote the time and resources necessary to honor commitments that contribute to the success of the project. One project director noted that collaborations are valuable but can be time consuming. Multitype organizational collaborations may be difficult as a result of differences in missions and levels of commitment.

Project directors repeatedly noted the importance of communication in the planning and execution of their projects. E-mail did not always facilitate communication for some projects. One project targeting gay men and lesbians reported that electronic and e-mail communication was a major factor in the success of their project. Nearly all review and discussion was done electronically, saving considerable time for everyone. However, telephone and face-to-face communication worked well for several projects and were ways to ensure that communications reached appropriate individuals. Project directors also noted the benefit of frequent communication with administrators and community leaders, one of the key findings from a review of public health outreach projects conducted between 1998 and 2001 (Rambo et al., 2001).

Reflecting on their decision-making processes, a number of project directors reported that working with a diverse committee could make reaching consensus difficult. Political and bureaucratic challenges emerged in the course of multiple projects. A project to develop a regional health information network reported that collaborations are complicated because of the participation of distinct organizations accustomed to relying on different approaches. When planning how decisions will be reached, project directors remarked that it may be helpful to identify one organization as having final authority. This is often the organization with financial control.

Conclusions

Project directors reported significant benefits from their projects, in spite of minor setbacks and unexpected problems. These projects led to increased awareness of health science libraries and the recognition that medical libraries are a source for assistance in locating health information for the users of public libraries. As a result of collaborations between health science libraries and public libraries, the public library began to perceive hospital libraries and academic libraries as resources for medical information. This type of collaboration fostered linkages between the collaborating organizations, leading to the sharing of resources and reference requests. Within many organizations, institutional administrators gained a greater appreciation of the library as a source of funding and in fulfilling the community service mission of the organization. Many organizations were able to add consumer health information to their Web sites, raising the library’s visibility. Several project directors reported that the project expanded personal networks that crossed professional boundaries.

Undertaking a new project within an organization that is already uti-
lizing its staff and resources to its fullest extent is not without challenges. Some of the project directors felt that their library staff were uninterested or overwhelmed by the additional responsibility of providing consumer health information. Insufficient funding was another concern that project directors raised. Occasionally, because of underbudgeting or unexpected expenses, they were unable to complete the project with the funded amount, resulting in the lead organization having to use its own resources to accomplish the project’s objectives.

The goal of the Electronic Access to Health Information projects was to improve access to electronic health information for consumers. The results of this first round of funding served as a starting point for NLM to focus special funding through the NN/LM for projects to promote electronic access for the general public. The projects reached a large number of individuals in many areas of the United States. The implementation of the projects enhanced existing partnerships and collaborations and created new ones. The participating libraries reaped positive benefits from their participation. The results convinced NLM that providing special funding for such efforts is an opportunity for NN/LM network members to expand their outreach to ensure that members of the public are aware of and have access to quality health information. The results of these efforts also highlight the need for involvement of the community in identifying, planning, and implementing activities that address their health information needs. In addition to providing funding for another round of these projects, the NN/LM also is piloting a set of Community Outreach Partnership Planning Projects, which provide funding to libraries to support intense involvement of community partners in the assessment of community information needs and the planning of community outreach projects. The hypothesis is that these planning awards will yield proposals that will have the full support of all partners involved.

References


Building Community Bridges for Health: Consumer Health Librarians as Health Advocates

Michele A. Spatz

Abstract

Consumer health librarians can and must function as health advocates within their communities, fostering and strengthening local health initiatives by joining community partnerships and providing health resources. Through their unique and important role, health librarians of the twenty-first century will help push healthy community agendas. This article highlights strategies for health information professionals to leave the safe confines of the library, venture out, and make a healthful impact in the broader community.

Introduction

Consumer health librarians bring expertise on resources and materials relating to all aspects of health and medicine from disease-specific information, chronic medical conditions, therapies and coping strategies to lifestyle adjustments, prevention, emerging health threats, and medical research. Even the preceding description is just a portion of the depth of knowledge health librarians apply in their daily work.

Leading health indicators from the Healthy People 2010 initiative prioritize the most pressing public health issues facing the United States. According to the Office of Disease Prevention and Health Promotion (ODPHP), each indicator is an important health issue in its own right. Together, the indicators illustrate the myriad facets involved in achieving health for individuals, communities, and the nation at large. According to

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the ODPHP, public and private agencies must form collaborative partnerships to address these leading health indicator cornerstones:

- The information people have about their health and how they can make changes for improvement
- The healthful behavior choices people make
- Where and how people live
- The quality and accessibility of health care people receive (Healthy People 2010, n.d.)

The goal of Healthy People 2010 is to improve and prolong health while eliminating health disparities. Consumer health librarians are uniquely positioned to help communities tackle the first cornerstone: the kind and quality of health information individuals possess (Healthy People 2010, n.d.). If Americans are to meet the objectives of Healthy People 2010, librarians must be health advocates in their respective communities by partnering with like-minded agencies and organizations. In this way, librarians contribute to the greater good of the nation’s health.

**PARTNERSHIP PERSPECTIVE**

Partnerships are essential to healthy communities. The leading health indicators are borne of lifestyle choices, environment, socioeconomic factors, and the availability and affordability of health care services. The World Health Organization defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (Preamble, 1946). Since health is interdependent—combining biological, social, intellectual, environmental, and spiritual needs—no one entity or organization can significantly effect change. In forming or joining partnerships, librarians must understand and seek those relationships based upon sound principles of partnership. Such principles level the playing field for all participants by providing ground rules for both equity and accomplishments.

What principles of partnership foster success? A critical skill is to think outside the library. Typically, because of the interdisciplinary definition of health, organizations from disparate social sectors are represented in community health initiatives. For example, individuals from education, parks and recreation, social service agencies, and public health departments may form a collaborative network. Librarians must understand each agency’s unique role and distinct perspectives to help find common ground. Thinking outside the library helps librarians explore their special skills for the good of the group and, ultimately, the community.

Defining the scope of the partnership and the overall mission is essential. Members must have a clear understanding of their relationship to one another and the mutual goals that unite them. Clearly defined
responsibilities and timelines are crucial to the groups’ mission. While the timeline must be flexible to accommodate obstacles or new information, there must also be accountability to ensure progress. Each member of the partnership must have a stake in achieving success.

Rules of conduct foster trust. Such rules outline how communication occurs among partners. For example, members will engage in respectful communication without interruption; practice active listening; treat all ideas as valid; and reserve the right to pass on commenting.

Finally, accomplishments must be measurable. What is the group trying to accomplish and how does it determine success? Measurement provides a tool for evaluation and reflection. It contributes to positive and sustainable relationships by providing information to build upon or identifying problems to avoid in future collaborations.

**Librarians as Advocates**

How might librarians serve as health advocates in community partnerships? An obvious answer is by utilizing their deep mining research skills to

- Identify best practices
- Share relevant news stories and important research results related to community initiatives
- Compile trends data and other statistical information such as census data, demographics, morbidity and mortality data, and health status indicators

Such research or evidence-based partnerships provide a solid foundation for constructing local health initiatives.

Librarians may also contribute considerable, well-developed communication skills to health advocacy efforts through public service announcements, fact sheets, resource and referral lists, public education pieces, and Web site development. Such communication provides a framework to change community norms by integrating health initiatives into the fabric and awareness of community life.

Evaluation and quality filtering skills are vital to select appropriate, meaningful resources. Offering repository and collection development expertise in support of a partnership’s health initiatives is another way librarians act as health advocates.

Furthermore, consumers need help to become their own health advocates. Selecting trustworthy health information by evaluating quality and reliability is a librarian’s forte. Librarians’ intimate knowledge of such criteria enables them to reach consumers by identifying quality health information. Partnerships with other health advocates opens the door to a broader audience.
CONCLUSION

The recent news about the health of the nation is distressing. Approximately 61 percent of adults are overweight, as are 14 percent of youth. Because of this trend, Type II diabetes, heart disease, certain cancers, stroke, arthritis, and breathing problems are on the increase (U.S. Department of Health and Human Services, n.d.). Healthy People 2010 provides a blueprint for addressing the nation’s health by identifying fundamental concepts needing attention. Health information is a key component of Healthy People 2010. By applying principles of partnership and bringing their considerable professional skills to community health initiatives, librarians contribute to improving the nation’s health.

Now that’s advocacy!

REFERENCES
Philly Health Info: The College of Physicians of Philadelphia’s Regional Community Health Information Project

Andrea Kenyon

Abstract
The College of Physicians of Philadelphia has created Philly Health Info (PHI), a regional community health information model. PHI objectives are, first, to provide as many citizens of greater Philadelphia as possible with accurate, current, and understandable health information they can use to their benefit; and second, to test the feasibility of reaching a substantial proportion of people who are underserved through community sites such as library branches, community health centers, physician offices, and other convenient locations. The centerpiece of PHI is its Internet portal. This consumer-oriented portal focuses on regional health issues and offers a virtual directory of regional health resources and services. A pilot project was launched in the spring of 2004 to test the feasibility of bridging the digital divide by placing trained volunteers at Internet access sites in community locations. The first PHI site is located at the Northeast Branch of the Free Library.

Introduction
A new initiative designed to empower consumers and reduce the risks that accompany seeking health information on the Internet was officially launched by The College of Physicians of Philadelphia on Wednesday, April 21, 2004, at the Northeast Regional Library. Philly Health Info (PHI) is both a community health information system and a user-friendly Internet portal (www.phillyhealthinfo.org) created for the delivery of regional health information resources and services. Philly Health Info’s core objectives are

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first, to provide as many citizens of greater Philadelphia as possible with accurate, current, and understandable health information they can use to their benefit and, second, to test the feasibility of reaching a substantial proportion of people who are underserved by providing access to health information at neighborhood sites such as public library branches, community health centers, physician offices, senior centers, and other convenient community locations. The College has developed a network of community-based partnerships throughout the region that offer access and assistance for consumers seeking health information, as well as serving as a conduit for recruitment and training of volunteers to aid the public in accessing health information resources and services.

BACKGROUND

The College of Physicians of Philadelphia was founded as a private medical society in 1787 by the city’s leading physicians, including Dr. Benjamin Rush, a signer of the Declaration of Independence, and Dr. John Morgan, the founder of the nation’s first medical school. Today, The College is a nonprofit educational and cultural institution dedicated to promoting a better understanding of medicine and the roles of the physician in society. It has an honorary fellowship of some 1,500 physicians, other health professionals, and distinguished members of the laity. It is also home to one of the foremost historical medical libraries in the world and to the renowned Mütter Museum for the history of medicine. From its inception, The College has been dedicated to serving the health and medical needs of the public. An early by-law refers to “contributing in all ways to the health of the community.”

The College’s Division of Public Services has been optimally positioned to implement a regional health information network. In a city that hosts five medical schools and numerous health care systems, The College prides itself on its neutrality. It has nothing to sell and is committed to improving the health of the public. In 1983 The College developed Pennsylvania’s first coordinated effort to share the resources of health science libraries with public libraries and other agencies through the Consumer Health Information Network (CHINET), a consortium of public libraries, medical libraries, health libraries, health agencies, health care professionals, and consumers in Philadelphia, Bucks, Chester, Delaware, and Montgomery counties. Two years later, with funding from the Commonwealth of Pennsylvania, The College was able to expand its provision of these information services to state-supported institutions throughout Pennsylvania. The resulting program was called the Health Information Services for Pennsylvania Residents Program and focused on education and reference support services for nonmedical librarians.

The C. Everett Koop Community Health Information Center, created in 1995 with funding from the Connelly Foundation, provides access to reliable and current health and wellness information. The Koop Center
provides print material and Internet access free to the public and is open seven days a week, 10 A.M. to 5 P.M. The Centers for Disease Control (CDC) commissioned a formal evaluation that was highly laudatory of the Koop Center and its achievements. The College is now expanding the work of the Koop Center through the development of Philly Health Info.

The Philly Health Info Project has evolved under the leadership of Thomas W. Langfitt, M.D., the president of The College of Physicians and the former head of the Pew Charitable Trusts. In addition to Dr. Langfitt, the other members of The College’s PHI team are the Director of Public Services and PHI Project Director Andrea Kenyon, Consumer Health Information Specialist and PHI Web Manager Eric Darley, Outreach Coordinator Ellen Freda, and PHI Content Manager Susan Underkoffler.

**Philly Health Info Network Components**

*Philly Health Info Portal*

The centerpiece of Philly Health Info is a free, multifaceted, consumer-friendly Web portal that provides a comprehensive online Philadelphia regional health information directory to assist Philadelphia-area consumers in accessing health care services. The PHI portal has been designed to benefit everyone but provides specific resources for targeted segments of the population including seniors, women, minorities, children, and youth.

The home page features a health periodical that highlights a different health topic on a quarterly basis. The lead article is written by college fellows and other area health care professionals. A feature story highlights the activities, programs, and services of an area organization addressing the same topic as the lead article.

Early in the development of Philly Health Info the Philly Health Info Project Team decided to focus our efforts on locating, listing, and maintaining links to health resources in greater Philadelphia. At the same time, we understood, and continue to understand, the value of nonregional Web sites in providing comprehensive, general health information about a wide variety of health and medical topics. We selected ten of these “national” Web sites to serve as referral sources in the event that someone cannot locate information within Philly Health Info on a specific topic. Most of these national Web sites appear on the General Health Web sites page of the Consumer and Patient Health Information Section (CAPHIS) of the Medical Library Association. The “Top 10” list of national health information Web sites include Centers for Disease Control and Prevention, Hardin Medical Directory of Internet Health Sources, Healthfinder, Medem, MedHelp, MedlinePlus, MedWeb, National Organization for Rare Disorders, NOAH, and Mayo Clinic.

Philly Health Info currently provides an alphabetical list of links to information on eighty-five diseases and disorders and health and wellness
issues. The College supplements information provided by the “Top Ten” national sites with easy-to-understand health information from ADAM (medical encyclopedia) and Wired.MD (streaming videos).

The most unique feature of the PHI Portal is a directory of over 500 regional health and medical services and resources covering the 85 disease and wellness topics. The initial focus for the directory was on northeast Philadelphia in order to support the dissemination of neighborhood health resources and services at the computer kiosk located at the Northeast Regional Library. In early 2004 The College hired a full-time content manager, who provided the necessary person power to expand Philly Health Info’s geographic coverage to include the entire city of Philadelphia. In addition to pointing to regional resources and services Web sites, PHI works hard to identify and enter regional resources and services, support groups, agencies, and health-related events that do not have a Web presence. A template system was created to enter PHI content. The content manager scans local newspapers, and PHI staff is routinely picking up flyers, checking bulletin boards at supermarkets, and talking with community organizations. Future plans include expanding the regional services directory to include the four contiguous suburban Pennsylvania counties (Bucks, Chester, Delaware, and Montgomery).

The PHI Portal continues to be an evolving entity striving to provide a user-friendly interface for Philadelphians to access health information. The challenge is to expand the portal to meet these needs in an effective and efficient manner.

Visits to the portal are registered using a serverlog tracking product titled Index Tools. The PHI Portal offers multiple feedback options, including an online user survey, to solicit comments from users. Suggestions are also solicited from the PHI Portal Advisory Committee, which meets quarterly and is composed of librarians, public health professionals, health care providers, and medical informatics experts.

**Pilot Project**

In the spring of 2002 The College began plans for the launch of a pilot project in partnership with the Free Library of Philadelphia and the Philadelphia Department of Public Health to test the feasibility of bridging the digital divide through the intermediation of Internet access sites in neighborhood locations. After discussion with our outreach partners, a computer kiosk was installed in the Northeast Branch of the Free Library, which is adjacent to Community Health Center #10. Situated at the busy junction of Cottman and Bustleton Avenues, they are the busiest facilities of their kind in the city.

In preparation for the Northeast Pilot, the PHI staff team determined that a community assessment of the demographic characteristics, health status, and health information needs of Philadelphia citizens was necessary.
to assist in the implementation of the PHI project. The College contracted with the Philadelphia Health Management Corporation (PHMC) to include five health information questions in their Community Health Database 2002 Southeastern Pennsylvania Household Health Survey. The questions asked were

- When you want information about health, where do you primarily get it from?
- What type of health information do you primarily look for?
- What type of health information is the most difficult for you to find?
- How do you prefer to get information about health?
- Where do you primarily use the Internet?

In addition, PHMC conducted six focus group discussions with north-east Philadelphia residents. Numerous key informant interviews with north-east Philadelphia community leaders were also conducted during the spring of 2003. The findings from this community assessment showed that chronic conditions affected three out of ten people in northeast Philadelphia and that these findings presented an opportunity for Philly Health Info to provide an important public service to the community. The PHMC Household Health Survey indicated that younger adults are more likely to obtain health information from the Internet than other age groups. Certain groups also are more likely to obtain health information through the Internet; for instance, more Asian adults get information this way compared to white, African American, and Latino adults. Among adults who use the Internet, the majority access the Internet from home, followed by work. African American adults are much more likely to access the Internet at the library compared to other racial groups. The poor and uninsured are also more likely to access the Internet through the library than the nonpoor and the insured. The final PHMC report acknowledged that making Internet access available to diverse groups will present many challenges, such as the need to understand various methods of communication among population subgroups as well as issues concerning access to the Internet. In addition the report stated that copromotion with other social service agencies that are catering to the need for increased computer literacy training would be advantageous.

After a “soft launch” period during the winter months of 2003–2004, the PHI kiosk at the Northeast Regional Library was officially launched on Wednesday, April 21, 2004. The computer station, which consists of a desk with a computer, printer, and two chairs, is located on a landing in a highly visible location that still affords some privacy. Volunteers trained to assist patrons with health information questions are scheduled for two hour shifts on Monday, Tuesday, Wednesday, and Saturday from 10 A.M. to 2 P.M.

Visitation was slow at first but has increased due to media attention from local northeast newspapers and radio stations and referrals from the
Health Clinic nearby. Volunteers are asked to complete a questionnaire after each visit that records the topic the visitor requested and the volunteer’s search process. Visitors are requested to complete an anonymous survey to comment on their satisfaction with the service. Contact information is encouraged but optional. Contact information will be used for follow-up telephone interviews conducted by PHMC to determine how the information was used and if the PHI service was helpful.

Plans for expansion continue to surface as organizations learn about our project and want to participate. Agencies interested in hosting a kiosk or offering health information training using the PHI Portal include high-rise apartment houses called NORC’s (naturally occurring retirement communities), senior centers, physician group practices, and health centers. Three PHI neighborhood kiosks were launched in June 2004. Two will be situated at senior centers in different parts of the city and the third will be at the nurse practitioner–operated Eleventh Street Family Health Clinic in north Philadelphia. The goal is to test out the model in different environments and adjust the model accordingly.

Trained Volunteers

A unique feature of the PHI project is the use of volunteers, termed Interactive Personal Assistants (IPAs), to staff the community kiosk locations. Trained IPA’s are computer literate people from the community who help patrons access information using the Philly Health Info portal. The IPA serves as a community-based intermediary to assist in bridging the digital divide. A two-day hands-on training curriculum was developed in conjunction with the Drexel University Institute for Healthcare Informatics, under the direction of Russell Maulitz, M.D., Ph.D. The goals of the IPA training are to establish a comfort level for navigating the PHI Portal, to establish the role of the IPA and the parameters in which he or she will function, to identify probable, common difficulties that may be encountered and provide tools that may help overcome them, and to provide opportunities to role-play and work with the PHI site. There have been six training sessions with approximately seven volunteers in attendance at each session. A curriculum manual has been created, providing a copy of Powerpoint presentations from the class, guidelines for handling health information questions at the kiosk, practice exercises, and materials for further reading.

The recruitment and retention of volunteers has been a challenging aspect of the project. Initially there was some difficulty in recruiting volunteers. We subsequently posted IPA volunteer opportunities on the PHI Web site, www.opportunitynocs.org, and www.idealista.org. Additional volunteers have been recruited by community locations that want to offer PHI outreach. The challenge at the moment is screening new volunteers and keeping enthusiastic volunteers involved while kiosk locations are in their infancy stages, with slow patron traffic. Additional challenges involve
matching volunteers with appropriate outreach locations based on geography and schedules.

**Networking**

Community outreach has been critical in creating awareness of Philly Health Info and soliciting community participation. The outreach coordinator spent some initial time creating a list of community organizations to contact. During the first year of this project the focus was on organizations located or working in northeast Philadelphia. This has now been expanded based on opportunity and referral. We are now meeting with organizations throughout the city to determine ways that we can complement their community health outreach activities. A sampling of organizations we have contacted include faith-based organizations, social service agencies, community hospitals, academic medical centers, senior centers, support groups, health associations, and community-based coalitions. We have more inquiries about collaboration than we have time to explore and must constantly reprioritize our outreach activities. We have developed criteria for determining “partner readiness,” which includes stability of the organization and level of commitment to the PHI project on the part of the community organization, Internet connectivity and physical setting, visitor traffic and the nature of their needs, and the organization’s willingness to help promote the PHI program to their constituency.

**Future Plans**

Experience, funding, and opportunity are the three elements that continue to direct the PHI project. Experience has taught us that, while there is great interest in disseminating health to the community, there is no consensus on the best method for accomplishing this task. There are many stakeholders and plenty of bureaucracy and turf issues to overcome. Experience has also taught us that everything takes more time than is allotted, and understanding each organization’s culture, goals, and limitations are key to mutual understanding and trust. Finally, clear and routine communication between PHI and community partners is essential to prevent misunderstandings and provide reassurances of mutual commitment and cooperation. Opportunities to collaborate with community partners continue to grow. Future plans include placement of IPA-staffed computer terminals in clinical settings and expanding our neighborhood outreach to targeted locations in north and west Philadelphia. The challenge will be to secure the human and financial resources necessary to both respond to the opportunities for collaboration and to continually test and hone the PHI model.
Consumer Health Information from Both Sides of the Reference Desk

GAIL KOUAME, MARGO HARRIS, AND SUSAN MURRAY

ABSTRACT
This article addresses issues surrounding the provision of consumer health information in public libraries. Barriers to the use of public libraries by health care consumers are explored. Once a person has decided to try the public library as an avenue for searching for health information, interactions with library staff may still pose some challenges, both for the library user and for the librarian at the reference desk. Perceptions of the library as a place for health information often differ. Awareness of these issues can be helpful for both parties. The National Network of Libraries of Medicine can assist with training, Web resources, and funding for projects involving health information outreach to consumers.

INTRODUCTION

In an article that appeared in the Seattle Times on December 3, 2003, Jack Slater writes,

Conversations with doctors are often confusing for me. They might well have warned me about the [procedure], but I didn’t catch it. They carefully explain things to me, and I make like the intelligent, deeply comprehending person I wish I could be. I nod and furrow my brow. The doctors’ words run down one of my deep furrows and keep right on running, out to the foggy sunset. My wife is usually with me at these appointments, taking notes. Then, while driving home, she...
tries to explain what was said. I just can’t focus on all the variables.
(Slater, 2003)

While Slater is able to express his experiences with humor, with which we can all probably relate, it is also likely that his situation is all too common. Many health care consumers do not lack for health information, but instead are overwhelmed by it. In the example of Jack Slater he states that it is not until after his interaction with his physicians that he begins to attempt to process the information he received at his appointment.

Patients and consumers are taking more responsibility for their own health care as the health care system increasingly involves patients and families in treatment decisions. Patients want to participate in shared decision making. Also, patients are having to be more assertive due to Health Maintenance Organizations and insurance constraints on usage of the health care system. However, in order to make the best decisions, people need not just access to information but time to process and evaluate the information they receive. They also need reliable, accurate information in a digestible form. The question becomes, How can health consumers access quality health information, judge its reliability, and decide what to do when given many choices? Also, where do librarians fit into the scheme of helping consumers with these questions?

People faced with health care decisions need to be informed, and certainly “healthcare providers are the preferred information source when individuals need treatment for a disease or condition, but . . . other sources of information—such as public and medical libraries, pharmacists, and community organizations—also play an important role in providing health information” (Lyon, 2001, p. 107). While public libraries may not be the first stop (see Nancy Press’s article in this issue), it has been discovered that a good percentage of health consumers do end up in public libraries in their quest for health information.

This article addresses issues surrounding the provision of consumer health information by public libraries. We will discuss barriers to the use of public libraries by health care consumers. We will also examine the interactions between library users and reference staff once a person has made the decision to try the public library as an avenue for searching for health information. We will point out that patrons’ and librarians’ perceptions of the library as a place for health information often differ. We will also discuss perceptions and expectations of library staff members from both sides of the reference desk—both patron and librarian. Lastly, suggestions will be offered for finding the middle ground, where people on both sides of the desk can better understand each other. The role of the National Network of Libraries of Medicine will also be described.
Barriers to Accessing Health Information in Public Libraries

Mary C. Chobot’s analysis in the booklet “The Challenge of Providing Consumer Health Information Services in Public Libraries” is very thought provoking (Chobot, 2003). The demand for consumer health information in insatiable but, as other authors note, some consumers are “still on the sidelines” (Tu & Hargraves, 2003). In fact, some consumers have not yet entered the library seeking expert help from library staff. While the library can be the first access point to additional information resources, some potential patrons have not yet overcome the barriers of walking through the library door, speaking to a librarian face-to-face, or visiting the library Web site from home or another community location. How do public librarians overcome the challenges that keep some patrons on the sidelines, or reach out to community residents who are not yet library users to share important health information resources?

One dilemma may be that we tend to believe that public libraries serve a “general public” or that a selection of general health references serves all or even most patrons. Librarians have quickly learned that their patron audience has never been more diverse. They confront language and cultural challenges, literacy challenges, technology challenges, age-related issues, and a range of sensitivity and emotional issues before they even get to the body of health information resources in the library or available online. Many health care consumers have learned the phrase “medical home.” At the core of a medical home is your “family doctor.” The goal is for everyone to have a medical provider who knows him or her and provides the bulk of his or her medical care. For libraries, a community resident may need to recognize a “library home”—a library where they can go and be included and respected, find resources that meet their needs, see materials in their language at a reasonable literacy level, feel welcome, and are invited in to participate.

Chobot quotes one community health librarian who says she “would rather fill her shelves with the most usable information and not necessarily the most diverse” (Chobot, 2003). Her users (those who come through the door) are primarily white Americans over the age of fifty. She continues, “You learn to know what your community wants and you stock what they need” (Chobot, 2003, p. 2). While that sounds reasonable, it does not address the needs of residents not yet reached. When it comes to consumer health information, librarians need to consider more outreach to their communities to learn what their whole community needs. If community members do not perceive the library as a place to find the answers to their health questions, they will not visit—in person or online.

The Center for Children with Special Needs, a program of Children’s Hospital and Regional Medical Center in Seattle, was privileged to receive a
National Network of Libraries of Medicine (NN/LM) Access to Electronic Health Information award. The work of the project gave center staff an opportunity to work with parents of children with special health care needs and a remarkable group of dedicated librarians working in community-based libraries in Washington State. Ideas from both parents and librarians and the work of the project will be shared in this article. The early part of the project included parent feedback groups conducted in English and Spanish with parents of children with special health care needs. One of the parents at the feedback groups noted that the most valuable Internet resource for her family was the National Organization for Rare Disorders site. To get full-text articles from this Web site, a library must subscribe. Since her library does not subscribe, she does not visit the library. It is a challenge for librarians to know what potential patrons need or what health information resources might bring them into the library and make them regular library users. One strategy might be to utilize neighborhood or community focus groups to guide materials selection and health-related Web links on a library’s Web site. If a library is unable to provide requested subscriptions or text materials, a librarian can explore interlibrary loan or a relationship with an area medical library to supplement existing resources.

**Filling in the Gaps**

Often in the library’s health book collection the needs of a more general audience are well met. If you review the health links on library Web sites, you will find a grouping of useful, general health Web sites and searchable databases. If you have a more specific need, such as my clients’ focus on information about children with special health care needs, you may find your information search more frustrating, less satisfying, and more time consuming. Librarians have done a good job meeting the needs of the general health information consumer, but one of the challenges they now face is being more responsive to the special needs health consumer. As librarians review their current users of library resources, it might be useful to consider who from the community is missing and consider outreach activities to reach those missing patrons, offering and promoting health information resources to reach special or less common health information needs.

Library staff sometimes feel they are not experienced enough to respond to special health information or health care needs requests. Every librarian has his/her favorite topic, and health may not be on the “favorites” list. As I approached regional public library systems about participating in our NN/LM project, some public library staff were familiar with the Regional Medical Library (RML) and were taking advantage of resources available there. Others had never been in touch with an RML or did not know of the services available. Some library staff were hesitant to contact a hospital-based medical librarian for assistance with consumer health
questions. There was a sense of intimidation by that “expert,” as well as a concern that hospital-based medical librarians were not funded to serve community members. As the complexity of consumer health information being searched increases, there is an even greater need for those community-based librarians to interact and collaborate in an efficient way to support consumer health information needs.

Start at the Beginning

While libraries and their resources are very familiar to library staff, they may be mysterious to the infrequent library user. One helpful point raised by Phil Agre in his article “How to Help Someone Use a Computer” is that “You’ve forgotten what it’s like to be a beginner” (Agre, 1996). It is hard for library staff to consider that a visitor has never been to the library before or that a visitor has not searched on the Internet. Even more difficult to imagine is a long-time library patron who has not used the library for health information but now has that need. It is easy for library staff to assume a patron is knowledgeable and able to use the wealth of library resources to seek consumer health information. For some, an orientation or introductory tour is needed first to enable patrons to take a new look at library resources with their new consumer health information focus. More and more libraries subscribe to health databases and real-time services such as Ask Us 24/7. These may be exactly the resources that patrons seeking consumer health information need, but they may be unfamiliar with how to use them. Librarians are challenged with designing strategies to support adult learning when many adults are uncomfortable asking for the help they need.

In feedback groups and workshops with parents of children with special health care needs, parents acted surprised and almost unanimously noted, “I never thought of going to the library or asking a librarian for help. I thought I was supposed to be able to find anything online, and I should just do that” (Parent Focus Group, 2003). Those same parents admitted frustration and being overwhelmed by the number of “hits” they got when they searched the Internet for consumer health information. They expressed concern that they did not know whether a site was credible or not or who to believe. Still, they did not seek the advice of a librarian. Chobot notes that “Many public libraries assist their users in finding reliable health information online by providing lists of evaluated sources on the library’s web site” (Chobot, 2003, p. 9). Parents also appreciated receiving these links on paper handouts. If a parent was too uncomfortable speaking directly with a library staff member, print information available without asking was an acceptable substitute.

Parents are a good source of suggestions on how to make it easier to find consumer health resources in the library—online and offline. These can be simple solutions. A frequent request from parents is a short printed
list of two to three “starting point” Web sites on specific health issues. Sometimes there is a delay in receiving information when an interlibrary loan is necessary. Often a parent feels that his or her need is urgent, and some information is needed immediately. One parent described it this way: “If I visit the library and the item I want is not available there, I’ll wait for interlibrary loan. But I like to leave with something in my hand. My librarian finds an article or some information she shares and hands to me. I know the librarian listened to me and tried to find something for me to read right now. That means a lot to me” (Parent Focus Group, 2003).

Complementary Roles

Two very different roles merge when a patron approaches a library staff member for consumer health information. On the one hand, those roles are complementary—health information seeker plus health information expert. On the other hand, they may not be well understood by both parties. One of the things we have learned in workshops offered in the state of Washington is that parents of children with special health care needs have some interesting ideas about what librarians do in 2004. At the same time, librarians have some interesting ideas about what the parents know and do in the library! In our NN/LM project, parents and librarians are working together as a team to develop activities to share information, bring more parents to the library, and connect parents with health information specific to the topic of special health care needs. The conversation and exchange of ideas that happens in each pair is invaluable. One of the early realities discovered by the parents is that the person behind the library desk may or may not be a librarian. That was a surprise to them but not a remarkable concern. Whoever is behind the desk was perceived as someone interested in helping the parent with his/her health questions.

The Reference Interview

Consumer health information questions fall into what the Nebraska Library Commission (1994–2004) calls “special kinds of questions.” Health and legal questions fall into this category, and it is useful to share the commission’s major points about health questions here:

• “In answering medical and legal questions it is necessary to have a good understanding of the difference between providing information and giving advice.
• As with all questions, we can’t give our own personal opinions. We help patrons find information in our sources, but we don’t interpret the information for them.
• If you read something to a patron from a medical dictionary, you can’t tell the patron that the symptoms sound similar to the ones described by the patron.
You can do the following:

- Help locate books or articles on the subject.
- Show patrons how to use the books and indexes.
- Help patrons use directories of professionals.
- Help patrons identify other resources in the community that can help.
- Refer these questions as you would other questions, being sure patrons understand that they will be getting library information but not professional medical or legal advice.
- Caution your patrons that information in these areas is complex and changes quickly.
- Be sure you understand your own library’s policies and procedures on handling these questions.

MAJOR POINT: *We can help patrons find medical and legal information, but must avoid giving medical or legal advice* (Nebraska Library Commission, 1994–2004).

The commission makes clear and valid points. The challenge is that the patron does not always understand that this is the approach the librarian is taking, or blurs the line between health information and health advice. With the widespread availability of consumer health information, it is easy for the patron to generally categorize any information offered in the library as medical or health information and not to recognize or believe they are requesting medical advice.

Allcock and others provide helpful explanations of the reference interview. Allcock notes that patrons come to the library at any point in their health care, diagnosis, or information search. They may be looking for information for themselves, other family members, or friends (Allcock, 2000). Allcock refers to McClure: “Conducting a reference interview is a vital component of helping the patron find relevant information. During the interview, the librarian seeks to identify the users’ specific need for health information by asking specific questions which aid in defining their need” (Allcock, 2000, p. 22). Allcock continues by adding:

> The purpose of the reference interview is to help clarify the question asked by the library user in order to direct them to information sources which will answer the question. The librarian’s role is to direct the user to information, not to answer the question based on personal knowledge. This is an essential point, particularly with health information. It is important to substantiate all information in reputable sources. (Allcock, 2000, p. 22)

Again, the author offers clear and valid points, and they are points that may not be understood by the patron. To borrow from Phil Agre once more: “If it’s not obvious to them, it’s not obvious” (Agre, 1996). Library staff may formally or informally implement a reference interview, and it
is a basic tool of library practice. Some editorializing or explaining why librarians do what they do in the reference interview may resolve some misunderstandings or discomfort. One remarkable comment from a parent feedback group was from a parent who had been disappointed when a library staff member asked her how to spell her child’s condition. “Why is she asking me how to spell it? She’s a librarian; she can spell everything” (Parent Focus Group, 2003). Basic strategy to gain clarity and accuracy of the term was perceived as insensitivity. What library staff do in a reference interview, how to search online, and how to use different subscription databases—either at the library or remotely—are all strategies that may not be obvious to patrons who want and need the benefits of those tools. If a parent comes to the library in less than a calm state or is just overwhelmed by health information or a diagnosis that has just been received, an oral explanation of library tools may not be helpful. Printed materials that review those resources and a printed list of two or three useful health Web sites as starting points may serve the patron well later, at a calmer time.

Providing Library Assistance without Face-to-Face Interaction

Some parents acknowledged that they needed health information, but they were unable to ask a librarian directly for assistance. In our NN/LM project workshops, parents suggested a number of strategies librarians might use to help parents get needed information while avoiding direct contact or direct verbal requests. Some of these ideas included:

- Increasing health links on the library’s Web site
- Offering patrons a “short list” of Web sites as starting points for different health topics. Two to three sites, evaluated by the librarian, would be helpful
- Placing a service like Ask Us 24/7 that can be easily located on the library’s home page
- Making more information available in print
- Grouping book holdings on different health topics in a prominent way, making them easier to find
- Offering a written health information request form that might include two to three key questions that could be completed and handed to the librarian
- Offering free or fee-for-service PubMed searches via written request or an online form

Evaluating Health Information on the Web

There was an interesting discrepancy between parents’ and librarians’ beliefs regarding evaluation of health-related Web sites. There was total agreement that health Web sites, and probably all Web sites, needed to be evaluated. There was agreement that there was potentially dangerous information online. Librarians were eager to teach parents how to evalu-
ate health-related Web sites. Parents were eager to have librarians do that evaluation and share only evaluated Web site links with them. While it is certainly possible for parents in our project and other library patrons to learn Web site evaluation skills, confidence was expressed in the expertise and training of the library staff to complete this task. Parents were much more comfortable when either a library staff member or their health care provider offered health-related Web site links. The parents had a high level of discomfort if they were responsible for making that determination, even when given specific checklists or tools to use for the evaluation process.

Other Roles of Librarians

Another surprise for parents in our NN/LM project was the librarian’s role as a clearinghouse for community resources. From tax forms to voter registration, a public library offers many community connections. All the parents in our project are strongly linked with two important, statewide community organizations—Washington State Fathers Network and Washington State Parent to Parent Support Programs. These organizations offer resources to families with children with special health care needs in all counties in the state. Prior to our project, the parents had missed the opportunity to promote their organizations through the library’s channels. Librarians had missed the opportunity to share the resources with other patrons. Now library systems involved in the training project have information about the two organizations—online and in print. The library staff better understand the health information needs of these families, and they feel better prepared to meet that need when family members come to the library. Some of the library Web sites now include a link to the Center for Children with Special Needs, a program of Children’s Hospital and Regional Medical Center in Seattle. That link offers library patrons a starting point that is specific to special health care needs.

Sometimes Less Is More

The expertise and broad-based skills of public and medical librarians is nothing short of astonishing. Their profession and professional world is dynamic as more information is added, updated, refuted, and challenged. Yet library patrons show up at the reference desk or the main circulation desk expecting all questions to be answered—and not just answered, but answered quickly, correctly, and with great sensitivity! As librarians approach consumer health information, I suggest that less may be more, and patrons should be invited to guide the search and the depth of the information shared. Patrons can be prompted to ask for more information or for additional detail. It is easy to overload the consumer health information seeker with no obvious signs of that burden. Your patron may keep smiling and nodding his or her head even though information transfer has ceased. Librarians will still find themselves walking a fine line between pointing patrons toward the appropriate resources, and helping them use those
resources, and giving them the answer or interpreting the information. Librarians know well that there are times when a patron is unable to use the resource or understand the information shared. At those times, the librarian works within his or her professional processes and ethics to meet the information need. Parents (patrons) would only add, “It’s okay to show emotion if we show emotion. And please have a box of Kleenex . . . at every desk” (Parent Focus Group, 2003).

Publicity and Promotion

One additional consideration for library staff is the need to promote what they do in a community. Public libraries are a treasure in neighborhoods nationwide. Sometimes they are an area’s best kept secret. Libraries have changed with the times and kept up with the Information Age. Patrons and potential patrons have not kept up quite as well in their understanding of what libraries do! We would encourage all libraries, regardless of location, to develop and implement a marketing plan to share that richness with the larger community. It is important to tap patron feedback, but needs assessment and feedback must reach beyond current users. Publicity and promotion may cause your library seams to burst, but no library or librarian wants to miss an opportunity to reach new patrons. Know that outreach activities are critical to reaching those community members still unfamiliar with your services or still on the health information “sidelines.” Refuse to believe that residents are not visiting you—online or in person—because they do not need or want what you offer. You have a whole world of patrons that fall into that elusive category—not yet reached. The ultimate challenge for you is to bring those community members through your real or virtual doors.

The Librarian’s Point of View

The barriers that consumers face in accessing health information in libraries have been discussed, but what are some of the problems that librarians encounter in providing health information to consumers?

In a 1990 survey of public libraries in Ontario, Canada, reference librarians reported that the major problems they experienced in providing health information were incomplete or unclear queries from consumers, lack of adequate and appropriate resources in library collections, and a reluctance to provide health information for fear of being perceived as giving medical advice and interpretation.

In “Conducting the Reference Interview,” the authors state that

A librarian once told us that her least favorite reference questions concerned legal and medical information needs. Both types of queries undoubtedly present special challenges, especially for public librarians, who are unlikely to be specialists but have to cope with unfamiliar terminology, complicated or inadequate resources, and tricky ethical issues (including the ‘information vs. advice’ problem). In addition,
users who need consumer health or legal information may be reluctant to disclose the problem to the librarian. (Ross, Nilsen, & Dewdney, 2002, p. 157)

Some strategies to help reduce confusion and discomfort are discussed below.

**Pressures Librarians Face**

There are several practical and psychological pressures that librarians face in providing health information to consumers:

- Difficulty in keeping up in a quickly changing area
- Difficulty in utilizing specialized medical terminology
- Consumer confusion regarding limitation of the librarian’s role in providing information, not medical advice
- Needing to find out what the user really wants to know. Consumers are often unaware of the nature of medicine or medical literature and ask questions that are too general, such as “Where are your medical books?” or too specific, such as “I was told to avoid infections after a surgical procedure, but now my doctor want to do a trans-rectal prostate test—isn’t that putting me at risk?”
- Being able to handle sensitive, emotional questions
- Gaining the patron’s trust and acceptance in order to probe for further details to answer their question

These pressures are magnified in public libraries where librarians are often generalists and need to keep up to date in many subject areas. Librarians can help alleviate some of these pressures by gently guiding patron inquiries to help them gain appropriate information.

**Consumer Expectations**

While ready access to electronic resources may have partially solved the problem of inadequate library collections, this has only raised consumers’ expectations on what and how quickly health information can be provided. For example, many consumers believe that everything is available on the Internet and for free. Developing and maintaining electronic health resources is a challenging and time-consuming undertaking. Educating and assisting consumers in evaluating Web-based resources presents far greater problems than print resources, as the Internet is dynamic and filled with Web sites with little quality control or standardization.

**Examples from the Consumer Health Information Service**

At the Consumer Health Information Service (CHIS), based at the Toronto Reference Library, we have been providing consumer health information (CHI) since 1992. We have dealt with a diverse range of users and encountered many challenging situations. One of our most difficult situations is when a consumer is seeking information on a serious health
condition for himself or herself, a family member, or a close friend. Often he or she is unaware of what the condition is or of a possible poor prognosis. Or the consumer does know the “bad news” but has difficulty in discussing his or her information needs. These requests can be very hard for a librarian who empathizes with what the user is going through—the user may be emotionally distraught and need privacy and time.

**Ethical Issues**

Many CHI queries present ethical issues: CHIS has had questions from consumers who wanted to stop taking their medication (such as discontinuing antidepressants) or wanted to take higher doses of medication (such as a consumer being treated for schizophrenia believing that their medication level should be increased). These decisions must be guided by health care professionals.

Consumers may turn to the library as a last resort for help. A woman brought in her baby who had a congenital condition. She had been told the baby had a poor prognosis and asked the librarian if her baby would be all right. While this high level of trust and confidence in the librarian’s ability to help is flattering, it puts a great deal of stress on the librarian. It is often difficult not to fall into the temptation to answer the question “What would you do in my situation?” Librarians must find ways to refer patrons back to their health care providers for any type of question that might start with “Should I . . .?”

**Communicating the Limits of the Librarian’s Role**

The limits of the librarian’s role are particularly difficult to communicate to consumers. Consumers often ask for advice when there are conflicting opinions regarding what treatment is best for a certain condition. One example of this would be the need to make a decision about hormone replacement therapy. When CHIS staff direct consumers to authoritative sources for definitions or suggest that they discuss treatment options with their health care provider, consumers sometimes remark “what good are the librarians” if we cannot answer their questions. This skepticism of professional ability can be difficult for some librarians to hear.

**Amorphous Nature of CHI**

Another problem is that it is difficult to put boundaries on what CHI is. According to Patrick and Koss, CHI is “anything that enables individuals to understand their health and make health-related decisions for themselves or their family” (1995, p. 4). Consumer perception is that almost everything is health information if it potentially affects their health. For example, we have received questions that range from whom to contact about idling bookmobiles, disinfecting public computer terminals, and even reducing the “down time” of the online resources that one patron claimed was making him/her sick.
Expectation of Customization

Many consumers have a limited understanding of how medical literature is organized. At CHIS we have had caregivers trying to get information on someone else’s behalf become frustrated when the information available was not customized to their specific concern. For example, one consumer was seeking diet and nutrition information for breast cancer. This patron was only wanting to see resources for breast cancer and was not interested in more general information about nutrition and cancer. They were unwilling to accept that the more general information might be equally helpful. Libraries simply cannot anticipate every special health topic that may be requested and tailor resources to address all needs. They can, however, educate patrons about the nature of medical information and that some general information can be applied to more specific situations.

Attributes of a CHI Librarian

The connection forged between a librarian and consumer is much closer when providing CHI than with most other subject areas. The emotional response of the consumer has been widely written about, but the qualities of the librarian providing health information have not been as widely discussed.

It takes a certain type of individual to thrive in a CHI service—the most important attributes being

- A genuine interest in helping others find information to make informed decisions
- Sensitivity to the emotional state of the consumer and their need for privacy
- Empathy and excellent communication skills
- An appreciation of the right for consumers to have access to a wide range of information that may present conflicting views (and some views not shared by the librarian)
- Good and nonjudgmental listening skills

When I was asked during a recent presentation to a health sciences university class if I hired staff with health sciences subject background, I replied that the attitude of the potential staff was equally as important as subject expertise. Patrons are especially invested in health information questions because of the direct impact their choices may have on their health or that of a loved one.

Guidelines for Providing CHI

Consumer health questions often arise out of personal needs and cannot be handled in a factual, impersonal way. The sensitive and sometimes emotional nature of these requests make some librarians uncomfortable. There are guidelines and courses that can help.

The National Network of Libraries of Medicine (NN/LM) funded Web
site, HealthInfoquest (National Network of Libraries of Medicine, 2003), has an extensive list of reference interview resources that outline the stages of a reference interview and provide examples of how to handle “in the news” and sensitive questions.

One particularly useful resource from Healthnet from the University of Connecticut Health Center (Lyman Maynard Stowe Library, 2000), provides the following guidelines to assist staff in handling personal health questions:

1. Determine why the person needs the information.
2. Be aware of the person asking the question.
3. Get as much information as possible.
4. Always check terms in a medical dictionary.
5. Do not provide a diagnosis.
6. Do not interpret medical information.
7. Understand that the specific information the person wants may not be available anywhere in the medical literature and describe the limitations of medical information.
8. Provide the most complete information needed to answer the person’s specific request. Provide referrals.

For several years the Medical Library Association has also offered a continuing education course to deal with a range of these dilemmas entitled “Face to Face: Strategies for Effective Consumer Health Communication” (MLA Net, 2004). There are also “trigger tapes” and videos that can be used for medical reference training (Health Sciences Library, 1995; King County Library System, 1986; University of Nebraska Medical Center, 2002). Several are listed along with the print resources in the references section.

The Role of the National Network of Libraries of Medicine

In 1998 the National Library of Medicine conducted a pilot project with public libraries to determine how training and other resources could empower them to be better equipped to answer health and medical questions. In this study, it was discovered that “health is a top-ten topic area and that a significant (but not precisely known) percentage of patrons seek health information at the library” (Wood et al., 2000, p. 321). They also discovered that “Some public libraries, especially smaller, more rural, or less economically advantaged libraries, seem to benefit significantly even from modest resources for enhanced health-reference materials or Internet-accessible computer terminals” (Wood et al., 2000, p. 321).

Currently, through the NN/LM, a training curriculum has been developed for public libraries to increase their confidence and skill in answering health-related questions. A Web resource has also been created to encourage public libraries to partner with members of the NN/LM and
other community health agencies in order to increase their capacity for
providing health information (National Network of Libraries of Medicine,
2004). Public libraries are encouraged to apply for funding to participate
in community outreach projects surrounding health issues. The project
described earlier in this article involving parents of children with special
needs and community librarians is an example of a successful community
outreach venture. There are myriad other possibilities. Of course, the re-
sources of the NN/LM are available to libraries regardless of whether or
not they receive funding. Also, many of the member libraries of NN/LM
are open to receiving inquiries from their public library colleagues and to
offer support and advice regarding medical information and strategies for
providing it.

At the forefront of the issues that arise in providing consumer health
information is the ongoing need to educate library patrons about the com-
plexity of health information. Librarians need to be sensitive to the fact
that not all patrons are familiar with the limitations librarians deal with
in providing health information. Patrons need to realize that there is not
always the “perfect answer” to their questions and that librarians will make
every effort to provide quality, authoritative, and balanced information to
support consumers’ desire to learn as much as they can about their health
concerns. There are resources (many of them listed below) to aid in pro-
viding quality health information services.

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Factors Affecting the Provision of Consumer Health Information in Public Libraries: The Last Five Years

MARY L. GILLASPY

ABSTRACT
Between 2000 and 2005 several changes have created an impact on libraries that provide consumer health information to the public. They include increased Internet connectivity; quality and amount of consumer health information available; realization that American lifestyles are leading to health problems; maturation of the consumer health movement and greater acceptance of it among health care professionals; emphasis on health literacy; and September 11th. Some changes were notable in 2000 but remain issues for providers of consumer health information. They include the number of health news items available in all media; the aging baby boomers and their impact on health care financing; less time for physicians and nurses to provide health information and patient education during regular office visits; and the popularity of complementary therapies. The impact of these issues on the provision of health information in U.S. public libraries is discussed.

In 2000 this author published an article entitled “Starting a Consumer Health Information Service in a Public Library” (Gillaspy, 2000). The present article expands on the basic information provided in the original document, noting especially what has and has not changed in the intervening five years that potentially affects consumer health information in the public library setting.

Walter Broadnax, who in 1995 was the deputy secretary of the Department of Health and Human Services, stated that families in 2015 will be

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health literate, by which he meant, “They make informed decisions about health issues. They understand the link between behavior and health. . . . We have a moral imperative to make health information available to every American” (Broadnax, 1995; italics mine). Fulfilling such a goal demands that public libraries be part of the network of health information delivery, and the phrase “moral imperative” implies urgency. However, in too many communities, public libraries are struggling with slashed budgets, reduced staff, and competing priorities. How can they meet yet another demand?

The truth is that as many as 20 percent of reference requests received by a sample of public libraries in the late twentieth century were health related (Wood et al., 2000), and that number may be far less than the actual total of people who search on their own rather than request reference assistance. Public libraries are critical to diminishing the “digital divide” in the United States; since in 2004 a full 95 percent of public libraries in this country offered Internet access. Significantly, 80 percent of library systems in the United States are located in rural areas, where access to quality health information might be limited without online systems. To illustrate how rapidly public libraries have become wired, only 28 percent of systems had Internet access in 1996 (Bill and Melinda Gates Foundation, n.d.), compared to the near-total access only eight years later. In other words, public libraries are meeting challenges, especially for economically disadvantaged citizens. The Gates report states that families with incomes of less than $15,000 per year use computers in public libraries at rates two to three times greater than families with annual incomes of more than $75,000 (Bill and Melinda Gates Foundation, n.d.).

This being said, there is little doubt that public libraries can enhance their consumer health services. An examination of trends and events that impact consumer health information (CHI) services in public libraries can elucidate areas where enrichment or improvement might occur.

**What Has Changed in the Past Five Years, and What Do the Changes Mean for Public Libraries?**

Seven trends or events have occurred between 2000 and 2005 that significantly impact the delivery of consumer health information in all settings, but particularly in public libraries, the institutions most invested in serving the information needs of all citizens in a community. These items include the following: (1) increased access to the Internet; (2) increase in the quality of health information available on the Internet; (3) realization that American lifestyles are leading to serious health problems, even in the young; (4) maturation of the consumer health movement; (5) increase in high-quality print resources for consumer health; (6) emphasis on health literacy; and (7) September 11th. Certainly other factors could be listed as having had an impact, but these seven are notable for the breadth and depth of change that has occurred because of them.
Increased Internet Connectivity and Access

Many more people have access to the Internet in their homes than was true five years ago; moreover, the Internet is far more ubiquitous in society generally than it was at that time. In a 2003 report the Pew Internet Project reported that 93 million Americans, comprising 80 percent of adult Internet users, had used the World Wide Web to search for health information (Fox & Fallows, 2003). This is a change from the 52 million Americans who had relied on the Internet to make health decisions in 2000 and the 73 million in 2002 (Fox & Rainie, 2002).

These data are contradicted, however, by a study from the Center for Studying Health Care Change. These researchers, who conducted a survey of U.S. households in 2001, found that 62 percent of American adults sought no health information at all, from any source, during the previous twelve months. Of the 38 percent who indicated they had searched for health information, a mere 16 percent of them used the Internet as their source. (They preferred books, periodicals, friends, or family members as sources.) Moreover, this group was overwhelmingly young, female, and well educated (Tu & Hargraves, 2003). The authors of the report note that these results portend “significant challenges . . . ahead in educating consumers about trade-offs among the cost, quality and accessibility of care” (Tu & Hargraves, 2003, p. 1).

Where does the truth lie? In fact, in terms of providing consumer health information in public libraries, it may not matter. Adults learn at the point of need, when learning is relevant to their life situation, and certainly health issues become pertinent to almost everyone at some point in their lives. Of the Internet users who do search for health information, the implication for services in public libraries is clear: computers with fast, reliable Internet access must be available for citizens who do not have personal computers or online access in their homes, who prefer anonymity, or who need professional guidance in using a computer or accessing quality information.

Quality of Information

The quality of Web-based health information is arguably much higher than it was five years ago, and it is also easier to evaluate and use. However, just because evaluation tools are more obvious and usable, it does not follow that users pay attention to items such as the authority of the source and the currency of the information. In fact, the report Internet Health Resources states that fully half of health information seekers check authority and timeliness “only sometimes,” “hardly ever,” or “never” (Fox & Fallows, 2003, p. 32). The Medical Library Association (MLA) posted the “Top Ten Most Useful Web Sites” for health consumers in 2002 (MLA Net, 2004). The Web abounds in authoritative, excellent health information, and educated consumers have learned to look for such signs of quality as the HONcode, assigned by the Health on the Net Foundation; federal government, academic medical
center, or nonprofit organization sponsorship; and similar imprimaturs of quality. Public libraries can help point their users to authoritative, reliable sources by linking to MLA’s “Top Ten” page or directly to the recommended sites themselves, as well as to others that are appropriate for local needs. They can also offer classes to help users learn how to evaluate Internet information or provide Web-based tools for imparting standard protocols for judging the worth of the information they find.

Health Effects of American Lifestyles.

The Healthy People 2010 initiative lists ten leading health indicators that are being used to measure the health of United States citizens over ten years. At the top of the list are physical activity and overweight and obesity (Healthy People 2010, n.d.). Other lifestyle factors, such as tobacco use, substance abuse, and responsible sexual behavior, follow the first two. Although health care professionals and both private and government programs have targeted physical activity and weight management in the past, these issues have received far greater attention in recent years, perhaps because of the growth of obesity in the young. “Youth Risk Behavior Surveillance: United States, 2003” illustrates both the nutrition and the exercise issues: in the week preceding the survey, only 22 percent of high school students had eaten five or more fruits and vegetables per day. Moreover, fewer than two-thirds of high school students had participated in vigorous or moderate physical activity in the week preceding the survey (Centers for Disease Control and Prevention, 2004). The American Academy of Pediatrics notes that the “prevalence of overweight and its significant comorbidities in pediatric populations has rapidly increased and reached epidemic proportions [and that] prevention of overweight is critical, because long-term outcome data for successful treatment approaches are limited” (Krebs & Jacobson, 2003, p. 427).

Adults are significantly affected as well. Evidence of the deleterious effects of poor lifestyle choices in the area of nutrition and physical activity may be observed based on many factors, including the addition of the medical subject heading (MeSH) Metabolic Syndrome X in 2002. This newly recognized syndrome is characterized by any combination of insulin resistance (a MeSH heading only since 1996), hyperlipidemia, hypertension, obesity, noninsulin-dependent diabetes mellitus, and increased risk for adverse cardiovascular events such as stroke or heart attack.

What does this mean in the context of public libraries? The implications for collection development are obvious. Additionally, programming for children and adolescents can include positive health messages, and parents who search for information on how to help their children and teens cope with issues of weight management, healthy eating, and exercise should be able to find current resources in their local public libraries.
Consumer Health Movement Matures

Another feature of the past five years is that the consumer health movement has become more mainstream and more accepted within the medical community. Indeed, increasing numbers of physicians communicate with their patients via e-mail, though this trend is far from including a majority of physicians, who in the main are reluctant to venture into such potentially risky territory. Moreover, not all consumers are interested in having any portion of their personal medical information online, even within “secure” Web sites, since the danger of its being misused is certainly present.

An article in the *Oncologist* features statements by both a medical oncologist and a thoracic surgeon about the use of e-mail with patients, which they both view as a positive development, if it is used appropriately. The oncologist notes, “As we negotiate the future of communication, it’s not a question of whether you want to communicate with people by e-mail, it’s a question of how” (Penson, Benson, Parles, Chabner, & Lynch, 2002, p. 561). The surgeon explains his belief in the positive nature of e-mail communication with patients by saying, “It requires some participation by the patients in their care, which is very important” (Penson et al., 2002, p. 561).

Both *BMJ* (“BestTreatments,” since 2004) and the *Annals of Internal Medicine* (“Summaries for Patients,” since 2001) now include special features that interpret the results of key treatment studies for patients. *BMJ* features a “click through” to relevant points in the actual article, should a consumer wish to explore a topic in depth. These tools complement the *JAMA Patient Pages*, which have been a staple of that journal since 1998.

Not only are some physicians communicating with their patients via e-mail and personal Web sites, but consumers are also actually seated at the table in some health decision-making scenarios. For example, the Cochrane Collaboration, which is an international organization that “produces and disseminates systematic reviews of healthcare interventions” (Cochrane Collaboration, 2004) and their effectiveness, and is a key player in the move toward evidence-based medicine, has included a consumer component since its inception in 1993. CCNet—the name of the Cochrane Collaboration’s consumer network—has members in more than fifty countries. The collaboration encourages all Cochrane groups to include consumers in their deliberations and communications, partly so that research topics that are important to the general public but get overlooked by the health professionals are identified and that outcome measures that are important to laypersons are noted (CCNet, n.d.). Entwistle, Refrew, Yearley, Forrester, & Lamont wrote about the advantages of involving consumers in health research, noting that lay people’s views can be identified through reading what they have written about specific health topics; consulting through surveys, focus groups, and related formats; conducting consensus conferences with consumers; integrating consumers into the assessment phase...
of research study proposals and reports; and including health consumers on working groups (Entwistle et al., 1998, p. 465).

In England the “expert patient program” has been in existence since 2002 (About expert patients, n.d.). Here laypersons are trained to become partners with their physicians in managing their own health. The goal of the training is to develop “the confidence and skills to improve quality of life and work in partnership with health professionals” (Shaw & Baker, 2004, p. 723).

Many other examples of these types of consumer inclusion exist. The examples illustrate the international nature of the consumer health movement and how it has become a part of health care entities as it has matured. Once again, public libraries have an opportunity to expand services to this population, which currently comprises a “minority of patients who have the resources [and will] to find out about their illness and . . . take an active part in managing their own care” (Shaw & Baker, 2004, p. 724). Not only do consumers like these, many of them dealing with a chronic condition, require a computer and the Internet, they also require medical textbooks to acquire in-depth knowledge of specific conditions and treatment options. Public libraries with an array of levels and formats in their consumer health collection, including the current editions of key medical texts, will be able to serve this population. The public library is the place that most of these consumers will use, since many of these people are located in rural areas and otherwise have little access to medical textbooks.

Quality of Print Materials

The fourth change has to do with print resources available in lay language. While some of these materials have been available for many years, the quality and choice has expanded greatly in the past half decade. The first edition of the *Gale Encyclopedia of Medicine* (Longe, 2001) was published in 1999; the second edition has been available since 2002. Following the success of this excellent consumer health resource, Gale Group published a number of other works, including the *Gale Encyclopedia of Alternative Medicine* (Krapp and Longe, 2001), the *Gale Encyclopedia of Cancer* (Thackery, 2001), the *Gale Encyclopedia of Genetic Disorders* (Blachford, 2002), the *Gale Encyclopedia of Mental Disorders* (Thackery, 2003), and the *Gale Encyclopedia of Surgery* (Senagore, 2004). The first edition of the consumer version of the *Merck Manual* was published in 1997; the second edition appeared in 2003, and it is available on the Web (Beers, 2003).

Two consumer health series that are particularly notable for their format, accuracy, and helpfulness are O’Reilly’s “patient-centered guides” (the first titles appeared in 1999), and Marlowe’s “first year,” which began publication in 2003. A group of outstanding books whose titles begin with *Mayo Clinic on . . .* also began publication in 1999. Though they are not
listed as a series, they are recognizably the same in format, accuracy, and currency. Other good print resources exist as well, but these examples represent some of the finest available, and the majority of them have appeared since the year 2000. Public libraries, especially those in rural areas, should own as many of these works as the budget allows and their client base demands.

Emphasis on Health Literacy

A fifth trend that has dramatically changed the landscape of consumer health information is the emphasis on health literacy, which stems from the alarming rate of functional illiteracy in the United States. Widely considered the most statistically valid and reliable data set of its kind, the massive National Adult Literacy Survey (NALS) of 1992 reported that between 40 and 44 million Americans functioned at the lowest level of literacy (level 1) and are able to engage in only the most rudimentary tasks requiring reading, writing, and computational skills. For example, while people in this group can sign their names and add up a bank deposit entry, they cannot find an intersection on a street map or enter information beyond their name on a social security application. Though 15 percent of the total level 1 group were born in another country, and 5 percent had documented learning disabilities, all the rest were lifelong residents of the United States and, presumably, passed through some portion of its public school system (National Institute for Literacy, n.d.).

Functional health literacy is defined both as “the ability to understand basic health care communications, such as prescription instructions and insurance forms” (American Medical Association, 2003) and as “the ability to read, understand, and act on health information” (Andrus & Roth, 2002, p. 283). Even the most basic health information is generally much more difficult to read and interpret than a street map or a simple form. As early as 1980 JAMA published the results of a study that compared informed consent forms from five national cancer clinical trial groups for readability and concluded that “informed consent documents may not be understood by a substantial portion of patients who sign them” (Morrow, 1980, p. 56). By 2004 the Institute of Medicine had quantified the number of people who “have difficulty understanding and using health information” (Institute of Medicine of the National Academies, 2004) as 90 million people, or nearly one half of all adults in the United States. The grave effects such poor literacy can have on patient compliance with treatment plans, let alone simply understanding their diagnosed disease or condition, is both obvious and well documented.

Public libraries can make a significant impact on improving this situation in two ways. First, they can include easy-to-read health materials in their collections, perhaps through linking to quality Web sites like the National Institute of Digestive, Diabetes, and Kidney Diseases (NIDDK). In May 2004
the front page of this Web site (http://www.niddk.nih.gov/) contained a prominently placed link to twenty-three “Easy-to-read Publications” about such common topics as hepatitis, peptic ulcer, and diabetes. Healthfinder (http://www.healthfinder.gov/), a particularly simple site to use, can be searched for “easy-to-read” and has the advantage of linking to information that is not limited to certain diseases or body systems. The health topics page on MedlinePlus (http://www.nlm.nih.gov/medlineplus/healthtopics.html) includes a link to easy-to-read pages as well. Even if print materials for adults with low literacy cannot be obtained because of budget constraints, the Internet offers viable alternatives, at least for common problems, and many of the pages are available in both English and Spanish.

A second way that public libraries can address the health literacy crisis in the United States is through continuing adult literacy programs. Many other agencies besides public libraries offer literacy programs, especially in urban areas; however, the public library is ideally the prime advocate for literacy and learning in a community. A U.S. Department of Education report from 2002 states that 17 percent of all public libraries offered some sort of literacy program conducted by their staff and using their resources. The larger the library, the more likely it was that they would offer at least one literacy program.

The most common such program, offered by 63 percent of the libraries, was adult basic literacy skills, which teaches adults reading at the fourth grade level and below (Fast Response Survey System, n.d.). Yet most of the simplest patient education materials are generally geared to a fifth-grade reading level, with a range that goes well beyond what a college student would find easy to understand (Davis, Crouch, Wills, Miller, & Abdehou, 1990). This situation is at the core of Secretary Broadnax’s moral imperative and demands attention across institutions, agencies, and disciplines. Public libraries that address health literacy—through collections, programs, and special events and promotions—are doing their part to alleviate the burden imposed on a large percentage of citizens by lack of language skills.

September 11th

Finally, the horrific events of September 11th have affected all aspects of global society. Certainly they have affected the provision of health information to the public, in that public librarians may be confronted with consumer health questions that have not arisen to any significant degree since the Vietnam era. A small but growing body of literature discusses health events and observations in various populations since September 2001. Deleterious health effects can be observed across populations in a time of global upheaval, which certainly describes the early years of the twenty-first century.

Two years after 9/11, a group of researchers published a consensus statement on what are called unexplained symptoms following exposure as a
combatant or support staff in a war theatre. Since unexplained symptoms, defined as “physical symptoms that provoke care-seeking but have no clinically determined pathogenesis after an appropriately thorough diagnostic evaluation” (Clauw et al., 2003, p. 1041), have been formally studied since World War I, the authors conclude that there is a “near certainty” (Clauw et al., 2003, p. 1040) that such symptoms will occur in the aftermath of the attack in New York City and subsequent military action abroad. One of the most helpful conclusions in the consensus statement is the finding that well-intentioned interventions often cause more harm than good, and the most hopeful is that “symptoms are likely to resolve with time” (Clauw et al., 2003, p. 1046). This powerful public health message is one that can be conveyed through public libraries, in addition to other communication channels, to an anxious public, particularly in areas where citizens have been personally affected by 9/11 and its aftermath. While the consensus statement examines primarily combatants, wars from the twentieth century forward have routinely targeted civilian populations as well as military forces. Vulnerable segments of the population, especially children and the aged, experience extreme psychosocial trauma that may heal slowly or not at all. Indeed, discounting psychological trauma, studies show that the “adverse consequences of physiological stressors are . . . [most serious] when individuals lack: 1) control; 2) predictability; 3) direction; and 4) social support” (Clauw et al., 2003, p. 1044).

Of course, the loss of these four entities is felt most keenly by people who are actually participating in or are part of war or terrorist events, but anyone who lacks these important qualities is subject to negative health effects. Many Americans have felt the loss of one or more of these qualities since September 11th.

Children are at particular risk, especially if they have directly experienced war or terrorism. Depending upon their developmental stage, they may blame themselves for events they do not understand; regress to an earlier stage; or become irritable, defiant, or violent (Joshi & O’Donnell, 2003, p. 277). Overcoming the trauma requires multiple levels of support from families, communities, and government. Additionally, graphic images of war released by the media may have significantly adverse effects on some children.

One need not be directly affected by war or a terrorist act, however, to suffer symptoms of post-traumatic stress and loss. A longitudinal study conducted in the first six months after 9/11 examined the adjustment process among adults who did not directly experience the event. Although symptoms of post-traumatic stress declined over time, they remained elevated six months later (Silver, Holman, McIntosh, Poulin, & Gil-Rivas, 2002, p. 1242). Events since that time may have exacerbated stress levels and symptoms, particularly among families who have relatives serving abroad in either a military or a civilian capacity.
In the face of dramatically altered global priorities, public libraries occupy a unique position with regard to an existing communication infrastructure. More than 16,000 public libraries exist in communities across the United States, and they are trusted sources of information for their patrons. Indeed, in the immediate aftermath of the Twin Tower attacks, the New York Public Library began fielding reference requests for topics as diverse as Islam, Nostradamus, and particulars of the Arabic language (Matthews & Wiggins, 2001). Enterprising public librarians built miniportals to direct users to quality information.

In November 2001 staff from the Illinois State Library and the University of Illinois Library Research Center initiated a study to determine how public libraries in the state had reacted to the events of September 11th. At that time, only 25 percent had initiated any special programming, and fewer than 8 percent had participated in community panels. However, more than half had mounted special exhibits, and nearly 60 percent had created and supplied resource lists to patrons (Library Research Center, 2002). Three years out from 9/11, an initiative called the September Project is recruiting libraries to host events large and small where “people across the country will come together at public places like local libraries to discuss ideas that matter. Through talks, roundtables, and performances, people will share ideas about democracy, citizenship, and patriotism” (September Project, 2004).

Whether or not public libraries choose to participate in this national event, the health implications of September 11th and its aftermath are profound. From helping parents assist their children with understanding confusing events and gruesome images in the media, to providing information to returning veterans and their families, to adding items to collections that will record the health effects of this era for posterity, public libraries have a vital role to play in meeting the September 11th–related health information needs of their customers.

**What Has Not Changed, and How Are Public Libraries Affected?**

As much as the world has changed since 2000, some trends that were observable at that time continue today. Health news remains ubiquitous; it is a staple of television news shows, newspapers, and magazines. The United States continues to be an aging society; yet, even with the first wave of the baby boom generation approaching retirement, the United States is facing significant challenges in the area of health care reimbursement. The health care environment in the United States continues to be one in which physicians and nurses, traditionally the purveyors of patient education, have less and less time to answer the questions posed by patients and caregivers. Finally, consumers continue to be interested in alternative, complementary, and integrative approaches to health care.
Health in the News

The explosion in biomedical information has, not surprisingly, translated into press releases, health segments on television and radio news programs, special weekly or daily newspaper sections, and Internet sites. This activity represents a trend that is more than five years old. Methods of disseminating the information have become more sophisticated, but the practice of creating news from health advances is not new.

One of the challenges inherent in the early release of information is helping the public understand that the nature of scientific advancement often means that research must be repeated in order to verify results. For example, Judah Folkman first envisioned the idea of angiogenesis at the beginning of his career, more than forty years ago, yet neither endostatin nor angiostatin, the potent antiangiogenesis drugs he developed, nor others in this category that have been developed by other researchers, had been approved by the Food and Drug Administration in mid-2004. Consumers do not always understand how important it is to prove both safety and efficacy and to determine optimal dosage and method of administration before making a drug widely available. The tension that exists between the need for safety and the possibility of a cure is nothing new in medicine. Any librarian who deals with consumers searching for health information will confront this issue at some point. Basic resources on the conduct of scientific inquiry cut across disciplines and are an important part of a public library’s collection.

Baby Boom Generation

In 2004 a member of the baby boom generation turns age fifty every 7.6 seconds; by 2023, 20 percent of the population—one in five Americans—will be older than 65 (Callimachi, 2004). This phenomenon is occurring at the same time as dramatic changes in health care delivery and financing in the United States. A balanced discussion of a single-payer system versus private insurers, government programs, or a combination is beyond the scope of this article. However, the health care financing conundrum facing the United States definitely affects the provision of consumer health information in public libraries.

The record-breaking number of births beginning in the United States in 1946 and extending through 1964, what is now called the boom generation, has altered every aspect of American life. Even if what some pundits perceive as a looming crisis in funding for both Social Security and Medicare turns out to be an exaggeration, no doubt this group’s retirement years will be vastly different from those of their parents and earlier generations. Although they are arguably healthier, fitter, and better educated than previous generations, the boomers will still face the health issues that arise with aging and may demand low-cost options for their care and minimally invasive therapies. Moreover, as the practice of medicine is changing to
include innovative treatment options and patients as partners in care, their need for quality health information may exceed that of any previous group of elders. Given that public libraries are central to their communities and easily accessible by all, their administrations will need to assess the information needs within this demographic and plan ahead for the queries that will inevitably come their way.

The impact of a large aging population on care-giving structures merits particular attention, especially as it affects consumer health information. Medicare is a system that was designed to address acute health care conditions, not chronic, long-term conditions like Alzheimer’s disease, Parkinson’s disease, diabetes, arthritis, some forms of cancer, and related maladies. Yet, these are the sorts of health problems that will affect an ever-increasing number of patients and families, as medical technology becomes even more sophisticated and effective than it is now (Edlund, Lufkin, & Franklin, 2003).

What can public libraries do to assist customers who find themselves needing to make decisions about care for a relative with a chronic, progressive condition? They can start by assuring access to government and private insurer information about long-term care insurance, what Medicare and Medicaid will and will not cover, and what the laws are in their states regarding living wills, durable powers of attorney for health care, and related economic and legal issues. If families opt to care for a family member at home, then the public library can assure a current collection in setting up a home health care situation, from the type of equipment needed, to cookbooks, to formation of a respite team, and more. The public library could even form a partnership with medical agencies (like home health), faith-based institutions, or senior centers to secure a support net for families who are caregivers. The models from community to community will be different, but assuring that the groundwork is laid in advance will lessen the impact of an increasing need for information associated with long-term care.

Time Crunch for Health Care Professionals

Physicians and nurses are unquestionably the best possible sources of health information and education for their patients. They remain the front line purveyors of such information. However, a number of factors—including specialization, vocabulary, literacy, language, and time—mitigate against these two groups of professionals being able to respond to all of the health information needs of their patients and families. In some states, such as Illinois, high rates for malpractice insurance are actually driving some physicians out of the profession, leaving rural areas bereft of specialties such as obstetrics and neurosurgery (Parsons & Chase, 2004). While librarians can never diagnose or prescribe or recommend one course of treatment over another, they can provide the expertise in health information resources
that will direct consumers to trusted sources that will aid them to work with their health care providers in making decisions about their care.

Alternative, Complementary, and Integrative Approaches to Care

What is today known as integrative medicine was, not so very long ago, derided as “alternative” medicine. However, Americans spend significant sums of money on various herbal formulations, chiropractic, homeopathy, and related therapeutic approaches. In 1992 Congress indicated that, in the interests of public health, it wanted alternative therapies to be studied. The National Institutes of Health established the Office of Alternative Medicine and began doing just that (Marwick, 1992, p. 957). Today there is a National Center for Complementary and Alternative Medicine, as well as an Office of Cancer Complementary and Alternative Medicine. The purpose of all this infrastructure is to subject various substances and systems (such as traditional Chinese medicine) to the rigor of the clinical trials process.

Today more information about safety and efficacy, especially of herbals, is known than ever before. Good safety profiles for the majority of herbals have, so far, been verified, though much research remains to be done regarding the effect of long-term use of these substances. Some herbs, however, in particular St. John’s wort, are now known to have serious, potentially fatal effects if taken with certain commonly prescribed medications like anticoagulants, antidepressants, and others (Williamson, 2003, p. 1075).

Despite the lack of concrete scientific evidence, Americans are using complementary therapies in increasing numbers. In fact, more than two-thirds of American adults report having used a complementary therapy and, of this number, nearly half continue to use one or more therapies over a period of years (Kessler et al., 2001, p. 267). Scientists are working to establish safety, efficacy, dosage, and administration, since the use of these remedies has persisted over more than fifty years and profoundly affects the delivery of health care in the United States.

Public libraries undoubtedly receive many requests for information about this topic. Mounting the best possible Web sites available on this subject, purchasing evidence-based databases like the Natural Medicines Comprehensive Database (http://www.naturaldatabase.com/), and partnering with medical libraries and pharmacists with knowledge of this field will assure that patrons will have access to the information they need to make safe, effective use of complementary therapies.

Conclusion

Is there a moral imperative to make health information available to every American? And, if there is, how exactly should this be done?

Given the great complexity of the issues connected to health care that affect people in the United States and around the world today, the im-
portance of providing such information is clear. Thanks to the Internet and the World Wide Web, availability to wired consumers is also a given. However, while almost everyone in this country theoretically has Internet access, through public libraries if not at home, the reality is that there are still at least two generations of Americans alive today who are unfamiliar with computers and are often unwilling to master the skills necessary to access information online. Moreover, people learn differently and require multiple formats and channels of communication to acquire knowledge effectively.

While the number and nature of individuals who actively seek health information is disputed, the number is almost certain to rise given the ubiquity of what is available, the ease of access, the health care financing dilemma, and the needs of an aging population balanced against a younger, “sandwich” generation confronted with numerous economic and social challenges. Making current, accurate health information available in multiple formats, where and when customers require it, remains the goal for which all libraries answering health-related questions must strive. A combination of strategic partnerships and carefully built collections is the best assurance that public libraries will meet the consumer health information needs of their customer base and satisfy the moral imperative for such a service.

NOTE
1. Details of this quality indicator can be found at http://www.hon.ch/home.html. Retrieved May 29, 2004, from this address.

REFERENCES


Consumer Health Information Services at Iowa City Public Library

Candice Smith, Kara Logsden, and Maeve Clark

Abstract
Iowa City Public Library recently completed an eighteen-month consumer health project entitled Expanding Access to Consumer Health Electronic Resources in Iowa City and Rural Johnson County, Iowa. This project included health-related computer classes, demonstrations, and programs and was funded by the National Library of Medicine through a subcontract with the National Network of Libraries of Medicine, Greater Midwest Region. The Iowa City Public Library project built on the work completed by the Iowa Consumer Health Information Project, an earlier subcontract also funded by the National Library of Medicine. The Expanding Access project was an overall success. Project goals were met while patrons and staff increased knowledge and skills using electronic consumer health resources.

Project Planning

Library Strategic Plan, Mission and Vision

The Iowa City Public Library’s (ICPL) Strategic Plan guided project planning. The library’s strategic plans run for five-year periods, and project planning began shortly after adopting a strategic plan set to begin July 1, 2000. Many individuals, including community members, board members, and ICPL staff, created the library’s strategic plan. The strategic planning process emphasized visioning for exemplary programs and services that
respond to identified needs in the community. From this process, the mission and vision for the library was created.

Library Mission

The Iowa City Public Library is an innovative, dynamic resource central to sustaining and encouraging a literate and informed citizenry. The library reflects and responds to the community and is committed to

- Equal accessibility for a diverse population
- Intellectual Freedom
- Life-long learning beginning with the young child
- Enhancement of cultural and leisure activities

Library Vision

The Iowa City Public Library will be the best choice for information, quality collections, outstanding programs, and exceptional service. The library will be a trusted civic, cultural, social, and learning center and a welcoming place for relaxation, the exchange of ideas, and interaction among people.

Strategic Plan Goals Support a Consumer Health Project

The Strategic Plan provided a framework for project planning. Specific goals and objectives related to a consumer health project include

Collections and Programs: Offer collections and programs that reflect community interests and support the library’s mission

- Provide excellent print and audiovisual collections
- Offer adult and young adult programs
- Increase programming on The Library Channel

Community Relations: Build community knowledge, pride, and support for the free public library

- Utilize media and strategic partnerships to maintain a highly visible and positive institutional profile
- Encourage regional and interjurisdictional collaboration

Accessibility: Improve access to the library, information, materials, services, and programs

- Be at the forefront in the use of technology related to information retrieval and delivery
- Make technology accessible through well-trained staff and regular user education
- Reach out to those who cannot or do not come to the library

A Tradition of Outreach Services

The Iowa City Public Library has a strong tradition of exemplary outreach services to organizations within our community that serve at-risk
populations. These include twenty-two outreach sites throughout the city and county, located in retirement residences, residential facilities for persons with mental or developmental disabilities, a senior center, neighborhood centers, a domestic violence shelter, and a chemical dependency residential treatment center. The library provides outreach collections at these locations because individuals who utilize the services often are unable to personally visit the library.

Identification and Description of Target Population

The target population included the Iowa City metropolitan area and rural Johnson County, Iowa. This geographic area was selected because the Iowa City Public Library serves Iowa City residents, area city residents through Iowa’s Open Access program, and rural Johnson County residents by contract with the Johnson County Board of Supervisors. The target populations include:

- Patrons who seek consumer health information in person at the Iowa City Public Library
  - Iowa City Public Library serves a population of 62,220 residents of Iowa City and 17,400 residents of rural Johnson County.
  - Iowa City Public Library serves the nonacademic information and recreational needs of the 29,000 students at the University of Iowa.
  - In fiscal year 1999 ICPL’s Information Desk staff responded to 42,908 questions patrons asked in person, 19,723 telephone requests, 673 questions while representing the library in the community, and 128 fax requests. Although specific data is not collected, up to 10 percent of these questions are related to health information.
  - Many residents of Johnson County towns including Coralville, North Liberty, Oxford, and Solon also utilize Iowa City Public Library’s collections, services, and Web page.

- Patrons who sign up for electronic consumer health information training classes
  - In fiscal year 1999 Iowa City Public Library staff provided training or tours for 595 adults.

- Persons who live at or visit targeted sites that receive outreach services from the Iowa City Public Library
  - Iowa City Public Library provides outreach collections for twenty-two community organizations that serve residents of Iowa City and rural Johnson County.
  - Iowa City has the fastest growing population aged seventy-five and over in the nation.
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Source: U.S. Census Bureau

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Source: U.S. Census Bureau
Assessing Community Consumer Health Needs

In 2001 the State Library of Iowa completed the Iowa Consumer Health Information Project (I-CHIP), a project funded by the National Library of Medicine through a subcontract with the National Network of Libraries of Medicine, Greater Midwest Region. The I-CHIP project created the Health Info Iowa Web page (see Figure 1) (www.healthinfoiowa.org) and included a database of resources designed to meet the consumer health information needs of Iowans. Iowa City Public Library staff participated in the I-CHIP project and, based on knowledge of local needs, felt that a community-level consumer health information project would benefit local residents.

By combining strategic planning for library services at a local level and evaluation of needs on a statewide level, the framework for a project began to emerge. The I-CHIP project identified many consumer health needs in Iowa. In determining the focus of a local consumer health project, ICPL reviewed the I-CHIP needs and identified the following as most critical for Iowa City and rural Johnson County:

Figure 1. Health Info Iowa homepage.
The public does not know what is available.
There is an institutional gap between public libraries and health science libraries.
There is a need for alternative and complementary medicine information.
There is an explosion of information to choose from.
There is a need for links to authoritative Web sites.
There is a need for adequate training for librarians and the public in finding and evaluating health resources.
There is a need for publicity and promotion regarding consumer health information resources.

Locally, we identified three critical gaps in consumer health information knowledge and skills. First, library staff needed training to provide effective consumer health reference services in the library, over the telephone, and via e-mail. Second, patrons seeking health information needed information and training to identify and use quality consumer health resources. And third, there was a need for information and training at established outreach sites that serve elderly, low-income, and minority groups in our community.

Establishing the Project Goal and Deliverables

After completing the needs assessment we established an overall goal, “To increase the health of residents of Iowa City and rural Johnson County, Iowa through improved access to high-quality consumer health resources.” To meet the goal, the following project deliverables were established:

- Use Health Info Iowa project work as a foundation for consumer health information services and resources in Iowa City and rural Johnson County.
- Create special pages and links on ICPL’s Web page that assist patrons to easily access peer-reviewed resources. An emphasis was placed on MedlinePlus clinicaltrials.gov Health Info Iowa Web resources Iowa City Public Library electronic resources
- Train Iowa City Public Library Information Services staff to provide effective consumer health reference services.
- Offer consumer health training for the patrons in ICPL’s computer classroom.
- Offer Internet accessible computers and training for one retirement residence, one community residential facility, one senior center, and two community neighborhood centers that receive outreach services from ICPL.
• Create a consumer health information training television program to play on The Library Channel, the Iowa City Public Library’s local access television channel.
• Sponsor two educational programs related to health promotion.
• Promote the project to the community.

**PROJECT IMPLEMENTATION**

*Online Resources*

Initially project staff designed Web pages that would direct patrons to recommended online consumer health resources. Links to these pages were placed in prominent locations within the library’s Web pages (http://www.icpl.org). In addition, the Library’s Science and Medicine Web page (see Figure 2) (http://www.icpl.org/resources/web/science.php) was updated to reflect recommended consumer health resources. In 2003 the library’s overall Web site was redesigned. This coincided with staff planning for continuation of project initiatives after the end of the project. Staff determined that it was more effective in the long term to maintain links

*Figure 2.* Science and Medicine Resources web page of the Iowa City Public Library.
on the library’s Science and Medicine Web page rather than maintain two separate pages.

Classes

Classes for Library Staff At the beginning of the project, a librarian from the State Library traveled to Iowa City to provide training. All reference librarians assigned to the Information Desk were trained to use Health Info Iowa, MedlinePlus, and Clinical Trials. Staff also received consumer health reference services training. Staff reported that after the training they felt more comfortable providing consumer health reference services and were better able to judge the quality and authoritativeness of online resources.

Classes for Library Patrons The classes for library patrons were held in the library’s computer classroom and offered on a monthly basis. Instructors included the library’s reference librarians and project staff. The classroom had twelve laptop computers attached to the library’s network as well as a presenter’s station with an LCD projector. Classes were scheduled at varying times so they were available to the widest range of people who might be interested.

During the training session, the instructor outlined basic tips for finding and evaluating trustworthy health-related information on the Internet. Part of this discussion included the HonCode of Conduct (http://www.hon.ch/HONcode/Conduct.html) principles of Authority, Complementarity, Confidentiality, Attribution, Justifiability, Transparency of authorship, Transparency of sponsorship, and Honesty in advertising and editorial policy.

Instructors demonstrated use of three Web sites: Health Info Iowa (www.healthinfoiowa.org), MedlinePlus (www.medlineplus.gov), and ClinicalTrials.gov (www.clinicaltrials.gov). The instructing librarian outlined each Web site’s content and gave a brief demonstration of the various ways to find information at each site. The formal portion of the class usually lasted one hour. Often an information question and answer session continued for another half hour or more while individual questions were answered. While there were multiple computers at each site, the best outcome came from the instructor working at one computer while the students sat nearby and observed. Occasionally someone would work on one of the other computers, going to the sites as they were discussed.

All attendees were given class outline handouts so they could follow along with what the librarian was demonstrating and discussing. The handout included a brief survey for the patrons to complete at the beginning of the program. Questions included current or former occupation, prior use of the Internet to find health information, specific health Web sites used, strategies to find online health information, and whether or not Internet access was available at home. The survey also requested permission to make a follow-up call to determine if the class changed their information-seeking behaviors.
Feedback from the class indicated that MedlinePlus provided the resources patrons were most interested in, and so the training tended to gravitate toward this resource. Health Info Iowa tended to have more interest from students; however, feedback indicated it was a Web page that was easily navigated by all and in-depth instruction was not needed. Clinical Trials seemed to have less general interest from participants, unless persons in the class had an immediate need for finding current clinical trials.

**Classes at Outreach Sites**

A large part of the project focused on classes taught at outreach sites located throughout the community. Initially, five outreach sites signed on to participate in the project. Each site received a computer and printer with Internet access and agreed to assist with scheduling, publicizing, and hosting consumer health classes taught by an ICPL librarian. The outreach sites included one residential care facility, one retirement residence, one senior center, and two neighborhood centers.

We learned early in the project that we overestimated the basic search skills project participants at the outreach sites would have. Basic Internet instruction was needed as a foundation before we were able to teach the online consumer health classes. Once we realized this, we developed a basic Internet use curriculum and subsequent consumer health classes were more successful.

The residential care facility that participated in the project was Chatham Oaks, located just outside of the Iowa City limits. Chatham Oaks serves persons with mental illnesses of varying degrees and types. One of the main goals of Chatham Oaks, aside from helping those who struggle with mental illness in their daily lives, is to help residents gain some element of independence. Part of this is accomplished through education, and the project’s classes fit nicely with this mission. Chatham Oaks’ residents learned about using the Internet, as well as locating online health resources. Classes were taught in a computer room that had several computers and printers, as well as a Chatham Oaks staff person who observed the classes and provided assistance if needed. The residents and staff at Chatham Oaks were very welcoming and excited about the classes being taught there, and turnout was always good. As noted above, the residents expressed early on that they needed basic instruction with computers and the Internet, so the library’s regular Internet class was modified for them. We taught both classes regularly, on an alternating schedule.

The retirement residence was Oaknoll Retirement Residence. Oaknoll has a very active, engaged community of retirees aged sixty-two and older. Oaknoll provides its residents with the opportunity to participate in a wide variety of educational and cultural activities, and its location near campus and within walking/driving distance of the downtown area means that the city’s and the university’s many offerings also are available to its residents. Many Oaknoll residents choose to live there specifically because of these attractions. Residents have a vested interest in life-long learning; consequently, project classes were always well attended there. Oaknoll has a
small but adequate computer lab with three computers, all of which offer Internet access, and this is where the classes were conducted.

It was a similar situation at the Johnson County Senior Center (“The Center”), which is located in downtown Iowa City one block from the library. The Center serves adults aged fifty years and older who live in Johnson County and offers a variety of classes and activities that support life-long learning and community involvement. The Center has a large base of volunteers who teach classes and assist with daily Center activities. The Center is a very popular and well-utilized facility. It offers a computer lab that has several computers, a printer, and a scanner. The library held both basic Internet and consumer health classes there, which always had attendees. Several people who use The Center also came to classes offered at the library.

The final two sites were neighborhood centers. Both are located in low-income areas of Iowa City, and both serve minority populations. The Broadway Neighborhood Center has a large African American and Hispanic population, while the other, Pheasant Ridge Neighborhood Center, primarily serves immigrants from the Sudan and Jordan. Both centers focus on strengthening neighborhood and community bonds, providing various services to families that could not otherwise afford them, and bringing different types of programming into the communities so residents could participate more easily. Each location had a designated computer area with at least two computers.

The directors of both of these sites were very optimistic about the health classes being taught at the centers, and they felt that they would provide a service that was important and useful to the centers’ populations. It is odd, then, that these were the two places where we had no success.

Several classes were offered at the Pheasant Ridge center, but attendance was always zero. No classes were ever scheduled at the Broadway center, despite several phone calls and visits in which possible class times and topics were discussed. The directors of each center were called and/or emailed at least once a month throughout the duration of the project, but they only responded a few times, usually to say that schedules were too busy at the moment.

In discussions with neighborhood center staff after the conclusion of the project, staff identified many reasons for not fully participating in the project. Obstacles included staff turnover, work overload, lack of space, and conflicts with other programs.

Educational Program for The Library Channel

The Library Channel, a local access television channel in Iowa City, originates at the Iowa City Public Library. The purpose of programming on The Library Channel is to extend library programs to a wider audience, to inform the community about library services, to promote reading and library use, to record community events of enduring interest, and to make
meetings and events at the library more accessible to the community via personal televisions. Community-use surveys show that Iowa City residents watch programs on The Library Channel and get information about library programs and services from messages that play when other programs are not running. The Library Channel is channel 10 on the city’s cable tier and is strategically located between the local ABC and PBS stations.

Because The Library Channel is used to share information with the community and extend library programs into homes, project planners decided to produce a television program that focused on finding and evaluating online consumer health information. Staff based the television program on the outline created for library classes. This program continues to play on The Library Channel, and anecdotal information indicates that patrons watch this program.

*Programs*

A large part of the library’s project was health-related programming created or sponsored by the library and presented in the library’s large meeting room. Because of community interest in the programs, seven programs were offered during the project, five more than originally planned.

The first two programs, entitled “Kids and Drugs: A Parent and Youth Discussion of Substance Abuse,” were presented in April 2002. These programs were created and co-sponsored with the Iowa City Community School District staff. Students and parents were encouraged to attend; in fact, teachers offered students extra credit for coming to one of the sessions with a parent. Parts of the programs were videotaped and continue to replay on The Library Channel.

We found this to be a highly successful way of organizing a program, and both sessions were very well attended. Different parts of each program were presented or moderated by a specific individual, teacher, group leader, or library staff member. In addition, library staff created a PowerPoint presentation to give information about online substance abuse education and information. Both programs were highly successful in that they resulted in interaction among students, parents, and educators, as well as ideas and actions being formulated for improvement of drug-free alternatives for students, both in school and in the community.

The third program presented was entitled “Planning for a Healthy Retirement” and was sponsored by the library. The main speaker was Geri Hall, an associate professor and director of the master’s program, University of Iowa College of Nursing and Advanced Practice Nurse, Behavioral Neurology, University of Iowa College of Medicine. She discussed important topics such as maintaining good nutrition, preventing age-related illnesses, and considerations involved in selecting retirement facilities. Senior citizens and middle-aged persons who were interested in learning about retirement options for their parents attended the program. This program was videotaped and continues to replay on The Library Channel.
During National Mental Health Month, the library sponsored three programs that were presented by the local Community Mental Health Center (CMHC). These programs were all videotaped and replay periodically on The Library Channel. The first of these was “Becoming a Parent—Maintaining a Mentally Healthy Pregnancy & Recognizing Signs of Postpartum Depression.” The speakers were Richard Michaelson, M.D., CMHC Psychiatrist; Charles F. Hesse, M.D., CMHC Board Member, the Nest Board President, and retired OB/GYN physician; and Mary Hanna, Ph.D., CMHC staff. They discussed topics such as physical changes during pregnancy, the use of medications while pregnant, diagnosing different levels of depression in pregnant women, health-related resources, and options for pregnant women.

The second program was entitled “Parenting a Teen—Helping Kids Cope & Realizing When Outside Help Is Needed.” A three-member panel led the discussion and was made up of representatives from the Community Mental Health Center, the counseling department of a local high school, and a local youth group. The final program was “Adult Children & Aging Parents—What to Do and Where to Go.” There were four speakers who presented: Kit Dinneen Crane and Ginny Hamilton-Lawler, both of the Community Mental Health Center; Steve Siglin of Elder Services; and Jeff Kellbach from Pathways Adult Day Health Care. The presentation focused on topics related to the care of aging parents, including their physical, mental, and emotional needs, and options and resources for them and their caregivers.

The library also hosted the program “Advertising & Girls: From Awareness to Action Workshop.” The goal of the program was to educate parents and students about the effects of advertisements on consumerism and body image. The speaker was Mare Sullivan, actress and activist from Los Angeles, and talks centered on the effects of different forms of advertising on young women. The event was co-sponsored by the Iowa Women’s Foundation, the Women’s Resource and Action Center, the Emma Goldman Clinic, the Domestic Violence Intervention Program, WISE, the Rape Victim Advocacy Program, and United Action for Youth. This program was very well attended, both by young women between the ages of eleven and fourteen and their parents.

Overall we were very pleased with the programs presented. The project served as a catalyst to bring community groups together to focus on health issues faced by persons of all ages. An added bonus is the periodic replay of the programs on The Library Channel. Most of the information shared in the programs is not time sensitive, so we continue to rotate the programs into The Library Channel’s play schedule.

Promoting the Project to the Community

Giveaways were created as a way to share project information with the community. The primary giveaway was a bandage holder. The bandage
holders were neon colors and had messages printed on both sides. The front side said “Good Health Information is just a click away!,” and the back side had the Iowa City Public Library logo along with URLs for the library, Health Info Iowa, and MedlinePlus. Because our primary promotion activities were in the summer, we also ordered cardboard fans with the message, “I’m a FAN of good health information!” along with the library’s logo and three URLs.

Promotion activities focused on three separate areas. The primary project promotion was at a booth rented at the annual Johnson County Fair. The project was also promoted at other community events, a radio talk show, and through requests for programs from community organizations.

Johnson County Fair We participated in both the 2002 and 2003 Johnson County 4-H and FFA fairs. The fair is held for four days in mid-July, and always draws large crowds. Annually the Public Libraries of Johnson County purchases exhibition space at the fair. The Expanding Access project joined with the public libraries to create a larger booth in both 2002 and 2003. One-third of the booth was dedicated to consumer health resources. A laptop computer and large screen showed online health sites, and a PowerPoint presentation was set to automatically run when the laptop was not being used for one-on-one demonstrations. Also, a local company provided a water cooler to dispense free water for anyone who stopped in the booth. The library booth was very popular, and the bandage holders, fans, and water were in high demand.

In addition to the exhibition booth, fair staff also made demonstration space available for organizations to share information about their programs or services. In 2002 the demonstration area was quite simple, consisting of a couple of long tables to set equipment upon and a group of about fifteen chairs located on a corner of the walking path through a main demonstration building. In 2002 we gave four demonstrations and had people stop by for each session. In 2003 the demo area was in the same spot, but this time it was cordoned off and better arranged. We presented three sessions and had people at each one. The demonstrations were based on the class curriculum converted into a PowerPoint presentation.

Other Demonstrations Three demonstrations were given to focus groups, conducted by the NLM, that centered on the MedlinePlus Web site and how to increase awareness and use of it. Attendees of the focus groups were medical office personnel and patients. The librarian’s part in the focus groups was to go in at an appointed time and give a ten-minute demonstration of the Web site. The demo was, in essence, a slightly shorter version of that part of the library’s regular health class. Not only was this a great opportunity to give back to those who provided the library with the grant money, it also gave librarians feedback on the Web site—what works and what is confusing.

In addition, Kara Logsdon presented two computer sessions at the We-
ber Elementary School Health Fair in Iowa City. The topic for the sessions was “Finding Good Health Information on the Web,” and it was geared toward students in the third and fourth grades. Kara was invited back to Weber School’s annual Career Day to talk about careers in libraries and different types of subspecialties.

Exhibits and Other Promotions Other promotional activities included library displays throughout the duration of the project, messages played on the Library Channel, and paid advertising on cable television stations that promoted the projects and the availability of consumer health resources at the library. Staff was invited to share information about the project on “The Dottie Ray Show,” a local community events program. Information and fans were also distributed at a community-wide ice cream social as a part of Iowa City’s Irving B. Weber Days, an annual celebration of Iowa City’s local history.

Evaluation and Conclusion

Part of our evaluation of the project came from the questionnaire given to class attendees. While this survey and its results are not controlled or scientific, they did give important feedback from patrons that we interacted with directly. At the end of the project, we had a total of sixty-four questionnaires providing feedback. This number does not match the total number of attendees because those from the county fair were not given the handouts, and some attendees at the sites did not fill them out. There were five questions that we measured outcomes for; two came from the handout given at the time of the class and three questions were asked after the class. Question one looked at the various ways attendees sought health information before taking the class. We received 165 tallies from all respondents, with medical professionals and the Internet being the sources identified the most (see Figure 3). The second and third questions asked attendees to rate how much they used the Internet to look for health information, both before taking the class and after (see Figures 4 and 5).

A large number of respondents, 45 percent, indicated that they used the Internet as a resource for health information before taking the class, and we saw that number jump to 75 percent after the class. The fourth question asked which Web sites attendees had used after taking the class; the largest number of tallies indicated that both MedlinePlus and Health Info Iowa were being used (see Figure 6). The final question asked the attendees whether or not the class had been helpful to them; 54 percent said the class was very helpful, 38 percent said the class was helpful, and 8 percent said the class was not helpful.

The numbers show us several things that are relevant to the project. First, residents of our community were already using the Internet to find health information. This comes as no surprise, as it mirrors a widespread and growing trend. The data also indicates that medical professionals con-
Figure 3. How attendees find health information (before class)—165 responses from 64 attendees.

Figure 4. Attendees’ use of the Internet to search for health information (before class)—64 attendees.

Figure 5. Attendees’ use of the Internet to search for health information (after class)—64 attendees.
continue to be a primary, trusted source of medical information for many; it follows that, if we want to educate people about other types of information resources, those should also be reliable and backed by sound research and trusted entities. The three Web sites we used in the classes were chosen, in large part, because of their trustworthiness and authority, and it seems to have made a difference as a large percentage of attendees used MedlinePlus and Health Info Iowa after taking the class. At the same time, Clinical Trials was not used very much, but this is probably due to its very specific type of content. Finally, a large number of attendees said that the class was helpful to them in some way. While the responses were not specific in terms of how the class helped, they certainly indicate that those who took the class benefited from it.

In summary, the project was a success. It achieved the established goal—to educate Iowa City and rural Johnson County residents about finding and using good consumer health information resources on the Internet. We were able to reach portions of our community that could benefit most from the project, and participants responded in a very positive way to what we had to offer. We established useful and mutually beneficial connections with different organizations and institutions in our community. A large number of the library’s staff—not just those who worked on the project—were introduced to useful Internet health resources and learned to use them effectively. Reference staff reported more confidence in providing consumer health information, and we incorporated the selection and provision of consumer health information services into our ongoing, routine work assignments and outreach services provided to our community.

NOTE
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About the Contributors

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MAEVE CLARK is a 1982 graduate of the University of Iowa School of Library and Information Science. She is Coordinator of Information Services at the Iowa City Public Library (ICPL), a position she has held since 1992. She is also the nonfiction collection team leader and is responsible for the selection of business and economics titles as well as reference materials at ICPL. Her earlier work experience includes Assistant Director/Head of Adult Service at the Carnegie Stout Public Library in Dubuque, Iowa, and Reference Librarian at the Ames Public Library in Ames, Iowa.

KEITH COGDILL is Outreach Librarian in the National Library of Medicine’s (NLM) National Network of Libraries of Medicine Office. Prior to joining NLM in 2002, Dr. Cogdill was a member of the faculty at the University of Maryland’s College of Information Studies, where he continues to teach as a member of the adjunct faculty. In 2004 he received the Medical Library Association’s Eliot Prize for a study conducted with Eileen Abels and Lisl Zach on the value of library services. Dr. Cogdill received his Ph.D. in Information and Library Science from the University of North Carolina at Chapel Hill in 1998, and he subsequently received a certificate of recognition from the Association for Library and Information Science Education for his dissertation research on the information needs of nurse practitioners. Since 2002 he has coordinated the development of phpartners.org, a Web site designed to meet the information needs of public health personnel.
MARY DIGGS-HOBSON retired from Xerox Corporation in 1990 as a regional project manager of education and training development to pursue a career in ministry. She graduated from RHEMA Bible College in 1992 and was ordained in 1996. Mary has spent the past fifteen years serving in the ministry of reconciliation, as a teacher, associate to Pastor Alfred Roberson of Trinity Faith Temple, and chaplain for Seattle hospitals and hospices, including Bailey Boushay, a hospice for individuals living with AIDS. Rev. Diggs-Hobson is the principal, founder, and consultant of Community Assets Network, a consulting firm whose mission is to strengthen relationships and communities by valuing people, recognizing and appreciating their assets, and amplifying what works well. She is also employed as a technical assistance project manager for the Nonprofit Assistance Center and served as a Commissioner on the Seattle Women’s Commission. Rev. Diggs-Hobson is co-founder of the African Americans Reach and Teach Health Ministry (AARTH). AARTH’s mission is to provide culturally relevant health care education, resources, and advocacy services for building the capacity of churches and faith-based institutions that serve people of African descent.

MARY L. GILLASPY manages the Health Learning Center, a consumer health library that serves the public, patients and families, and nursing and allied health staff of Northwestern Memorial Hospital. She was formerly the manager of the Learning Center at the University of Texas M. D. Anderson Cancer Center. She serves as the chair of the Regional Advisory Committee for Consumer Health of the National Network of Libraries of Medicine (NN/LM) Greater Midwest Region.

MARGO HARRIS is a health educator at the Center for Children with Special Needs, a program of the Children’s Hospital and Regional Medical Center in Seattle. Her career has spanned more than thirty years, with a continuing focus on patient education and consumer health information. She has been a long-time proponent of linking public libraries with consumers seeking health information, placing emphasis on literacy issues in the patron–library staff interaction. Margo’s work has allowed her to work in the hospital, school, and community settings. Her recent National Network of Libraries of Medicine (NN/LM) project, “Empowering Parents of Children with Special Health Care Needs: Harnessing the Power of the Internet,” has offered her another opportunity to link a health information–seeking audience with the resources they need. Margo’s work crosses age spans and a broad range of health conditions. Her recent articles in ParentMap, Northwest Baby & Child, and Seattle’s Child have shared important oral health information with the parents of young children.
MICHELLE HUDSON-OCHILLO is a second-year National Library of Medicine (NLM) Associate Fellow currently working at Arizona Health Sciences Library. Prior to the Associate Fellowship, she worked in medical, archival, and public libraries. As an NLM fellow, Ms. Ochillo presented a paper at the Medical Library Association’s annual conference in May 2003. She has also been responsible for poster sessions at the 2004 meetings of the Medical Library Association and the American Library Association on topics pertaining to health literacy and the Arizona Turning Point Project. In addition to her M.L.I.S. degree from Louisiana State University, she holds a Master’s of Social Work from Tulane University. Her professional interests focus on public health and medical informatics, with special interest in developing, implementing, and evaluating outreach programs targeting consumer health and underserved populations.

ANDREA KENYON is the Director of the Katherine A. Shaw Division of Public Services at the College of Physicians of Philadelphia and is responsible for all public programs and services offered by the college, including consumer health and museum education. She is Project Director for Philly Health Info and created the C. Everett Koop Community Health Information Center located at the college. A consumer health librarian for over twenty years, she is the co-author of a book entitled The Public Librarian’s Guide to Providing Consumer Health Information, published by the Public Library Association in 2002. Ms. Kenyon earned a B.A. in English from Ursinus College in Collegeville, Pennsylvania, and a Master’s in Library Science from the University of Michigan. She has held numerous positions in the Medical Library Association, including Chair of the Philadelphia Regional Chapter of the Medical Library Association and Chair of the Consumer and Patient Health Information Section. She is currently the CAPHIS list manager, a consumer health information discussion group.

GAIL KOUAME is the Consumer Health Coordinator for the National Network of Libraries of Medicine (NN/LM), Pacific Northwest Region. The NN/LM is comprised of eight regions across the United States and is funded by the National Library of Medicine to develop collaborations and promote awareness of and access to information resources for health professionals and the public. The Pacific Northwest Region serves five states: Alaska, Idaho, Montana, Oregon, and Washington. Ms. Kouame focuses specifically on facilitating delivery of quality health information to the public through collaboration with academic, hospital, and community libraries; health agencies and organizations; and community organizations, health advocacy groups, health ministries, and other mechanisms. Ms. Kouame received her Master’s of Library and Information Science degree from the University of Washington in 1999. She holds a B.A. in Sociology and Psychology from
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LALITHA KUTTY currently is a librarian in the Collection Access Section of the National Library of Medicine (NLM). In this position she is involved with the interlibrary loan and customer service activities of NLM. Prior to this, Ms. Kutty was the Consumer Health Librarian for the National Network of Libraries of Medicine (NN/LM) at the National Network Office of NLM. In this position she coordinated and promoted the consumer health outreach programs of the NN/LM. She also worked with medical and public libraries to determine strategies for meeting the health information needs of consumers and developed and conducted consumer health training programs at various libraries. Ms. Kutty has also worked for over fifteen years as Health Information Specialist for various private organizations, providing medical and legislative information services to clients at the National Institutes of Health and the Centers for Disease Control and Prevention.

KARA LOGSDEN is the Adult Services Coordinator at the Iowa City Public Library, where she manages Adult Programming, Outreach Services, Popular Collections, and the Volunteer Program. Kara was Director of the Patients’ Library at the University of Iowa Hospitals and Clinics, where she managed the Library’s Consumer Health Information Center. She also served on the Health Info Iowa managing committee and National Network of Libraries of Medicine (NN/LM), GMR Consumer Health Regional Advisory Project.

TAMMY L. MAYS, M.L.I.S., A.H.I.P. is the Consumer Health Coordinator for the National Network of Libraries of Medicine Greater Midwest Region at the University of Illinois at Chicago. She has co-authored a chapter on consumer health information for Decisions for Health, Level Blue (Holt, Rinehart & Winston, 2004). Tammy received her M.L.I.S. from the University of Wisconsin–Milwaukee in 1997. Prior to joining the Greater Midwest Region, Tammy was an Associate Fellow at the National Library of Medicine in Bethesda, Maryland. After completing the Associate Fellowship program, Tammy relocated to Wisconsin, where she was the Outreach Coordinator at the University of Wisconsin–Madison Health Sciences Libraries. Currently, as the Consumer Health Coordinator, Tammy is responsible for building a consumer health program for the region by developing instructional materials and presenting and exhibiting at professional librarians’ and health professionals’ meetings. She also trains public librarians, consumers, and health professionals to search the National Library of Medicine’s consumer health products and services.
SUSAN MURRAY is the Manager of the Consumer Health Information Service (CHIS), a service that assists Ontario consumers in gaining greater control over their own health through access to health information. She is also the Project Manager for the Complementary and Alternative Health Affiliate of the Canadian Health Network, a bilingual network of reliable Internet-based health information. Susan has spoken and written extensively in the area of consumer health information (CHI). She authored *Developing a Consumer Health Information Service: A Practical Guide* (1995) and writes a quarterly CHI column for the *Journal of the Canadian Health Libraries Association*. Susan has served as the President of the Canadian Health Libraries Association (CHLA), Chair of the Consumer and Patient Health Information Section (CAPHIS) of the Medical Library Association (MLA), Chair of the MLA Books Panel, and is a member of MLA’s Health Information Literacy Task Force. In 1999 Susan received the CHLA Award of Outstanding Achievement and is a Distinguished Member of the MLA’s Academy of Health Information Professionals.

EILEEN BEANY PETERSON, M.L.I.S., has been Librarian at the Neuro-Patient Resource Centre of the Montreal Neurological Hospital since 2000. She actively promotes the use of patient information and the awareness of health literacy issues throughout the McGill University Health Centre. Eileen works with other librarians and community organizations to enhance the flow of information about neurological disorders and diseases and related concerns to the people who need it.

NANCY OTTMAN PRESS, since 2002, has been Library Director and Assistant or Associate Professor at Mars Hill Graduate School, a postgraduate seminary and counseling school that specializes in issues of sexual abuse, domestic violence, mental health, and the faith-health connection. For twenty years (1982–2002) she was a librarian for the Pacific Northwest Regional Medical Library (PNRML), fulfilling the roles of Education Coordinator, Acting Associate Director, Resource Sharing Coordinator, and Consumer Health Coordinator. She was the Program Coordinator of the New England Region, at Harvard Medical School, for three years before that. During this entire time she worked with various groups to assess health information educational needs, prepared training materials, prepared Web training pages, and conducted extensive training and evaluation. Mrs. Press supervised the first two years of PNRML’s Tribal Connections Project, a seminal effort to address the unique health information training needs of a specific ethnic community (see N. O. Press, R. Sahali, C. Burroughs, K. Frank, N. Rambo, F. Wood, E. Siegel, and S. Fuller, “Program Management and Policy Issues in Information Outreach: Lessons from Tribal Connections,” *Journal of Health and Social Policy* 17, no. 3 [2003]:1–20.) Mrs. Press
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CANDICE SMITH, a 2001 graduate of the University of Iowa School of Library and Information Science, is in her first year as a Reference Librarian at Iowa City Public Library (ICPL). Previously, she worked in the Adult Services Department at ICPL, as well as in Technical Services at the University of Iowa Main Library. In addition to her work in the Reference Department, she selects nonfiction audiovisual materials and helps design and teach computer classes at the library. Working on the Consumer Health project at ICPL was her first professional experience.

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