

Application of Technology ■

Approaching Equity in Consumer Health Information Delivery: NetWellness

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Abstract The growing public interest in health and wellness information stems from many sources, including social changes related to consumers' rights and women's health movements, and economic changes brought about by the managed health care revolution. Public, hospital, and medical center libraries have been ill-equipped to meet the increasing need for consumer-oriented materials, even though a few notable programs have been established. The "Information Superhighway" could be an effective tool for sharing health information if access to telecomputing equipment and training were available to those with an information need. The University of Cincinnati Medical Center, with its libraries in the leading role, is delivering NetWellness, an electronic consumer health library service, to residents of 29 counties in three midwestern states. Users connect directly through the Internet, through regional Free-Nets, and by visiting one of 43 public access sites where networked workstations have been installed. The continued success of the project depends on developing partnerships, providing quality content and maintaining fair access.

■ *J Am Med Inform Assoc.* 1997;4:6-13.

NetWellness is a publicly and privately funded project to provide consumer health information to socioeconomically and geographically diverse populations. By providing an electronic library of resources on the Internet and establishing multiple free mechanisms for accessing those resources, it is hoped that residents in underserved urban and rural communities will benefit through improved quality of life. This case report places NetWellness in context, describes its development and operation, identifies key factors for continued success, and suggests further steps to continue efforts to facilitate access to consumer health information.

Background

Health Information Needs

Public interest in obtaining health and wellness information has grown over the last 30 years, largely from increased concern for personal health and increased emphasis on "patients' rights" and the "consumer's right to know." Marshall attributes it to the general consumer movement of the 1960s and to the women's health movement of the 1970s and 1980s.¹

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Presented in part at the AMIA Spring Conference, Kansas City, Missouri, June 1996.

This project was made possible in part by a grant from the Telecommunications and Information Infrastructure Assistance Program, National Telecommunications and Information Administration, U.S. Department of Commerce. This project also

receives support under the U.S. Public Health Service National Action Plan on Breast Cancer coordinated by the Office on Women's Health and the National Cancer Institute with funds provided by the National Cancer Institute.

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Received for publication: 6/14/96; accepted for publication: 9/16/96.

At the same time, government and professional events have reacted and fostered an increased awareness of consumer health issues (e.g., the American Hospital Association's *A Patient's Bill of Rights* (1975), Canadian and U.S. Court rulings in 1980 and 1981 on rules of informed consent,^{2,3} and similar initiatives in the United Kingdom (UK)).⁴ Gann provides background and an overview of the consumer health information movement, both in the UK and the United States (US).⁴

The information and referral (I&R) movement also began to take shape within public libraries during this time. Overall, a "raised public consciousness" brought many social issues into focus, and some public libraries began to respond by providing information resources and direct referrals to community agencies. Childers provides a contemporary examination of this movement, while Tiffit offers a brief historical account.^{5,6} Today, public libraries continue to be important sources of personal health information.

Health Information Services

More and more health-related questions are directed at public librarians; they handle questions on everything from fitness and nutrition to cancer prognoses and health hazard appraisals.⁷ Many public libraries have developed informal or formal programs to enhance consumer health collections and to offer community outreach services.⁸ Public libraries responding to this need face continuing problems of funding new collection development efforts, locating suitable materials,⁹ assessing legal exposure,¹⁰ and balancing community norms versus information needs on sensitive health issues, such as AIDS.¹¹

Increasing demands for consumer health information also affect hospitals and academic health sciences center (HSC) libraries. Serving patients and the lay public places additional demands on these libraries because their primary role is to serve health professionals.^{2,12,13} Medical librarians are also concerned about legal liability.³

Today, the general public's needs for health information are being met in various ways. In addition to enhancing their consumer health collections, some libraries have reserved or opened special facilities.¹⁴⁻¹⁶ Gartenfeld¹⁷ reports an exemplary program linking public libraries and a community hospital for interlibrary loan and reference services. Another interinstitutional effort, among academic, medical, and public libraries in Ontario, is reported by Marshall.¹ Other institutions with a history of providing health information include drug and poison information centers.¹⁸ Typically, they are sponsored by drug companies to

serve only health professionals¹⁹; however, there are exceptions, such as the Cincinnati Drug and Poison Information Center.²⁰

Most library-related consumer health services are delivered in-house. Electronic materials may be available, but remote access seldom is. While projects providing MEDLINE and other health sciences databases to remote users are common, few provide electronic access to consumer-oriented health information. Recent services such as OncoLink²¹ and NetWellness utilize the Internet and the World Wide Web (WWW) protocol.

National Information Infrastructure

Obtaining current health information increasingly involves consulting electronic resources. Many guides and reference sources are available on CD-ROM and online. Self-help groups on commercial services such as America Online, CompuServe, and Prodigy have become popular, as have Internet discussion groups.²² However, not everyone can afford computer and telecommunications equipment to take advantage of these resources. Furthermore, many areas of the country remain underserved by the telecommunications infrastructure.²³ People without practical access to electronic information resources, either through socioeconomic conditions or geographic limitations, are at risk of becoming "information have-nots."^{24,25}

In 1994, the National Telecommunications and Information Administration (NTIA) announced the Technical Information Infrastructure Assistance Program (TIIAP). This program was created to "advance the goals of the National Information Infrastructure (NII) initiative" and was designed to support projects which would, in part, "enhance the delivery of social services, such as education and health care."^{26,27} A key criterion for TIIAP projects was "eliminating disparity of access" and reinforcing American democratic values. Projects that would enable ordinary people, particularly minorities and other underserved populations, to gain the benefits of the NII at reasonable cost were encouraged by NTIA,²⁶ which also emphasized awareness of other relevant infrastructure projects and encouraged "multifunctional" activities offering a range of services.²⁷

Design Objectives

The NetWellness project is partially funded by an NTIA TIIAP award. It was designed to provide consumer-oriented health and wellness information to residents of a wide region, regardless of their socioeconomic or geographic situation. The University of Cincinnati Medical Center and other organizations in

the region formed the Ohio Valley Community Information and Technology Providers (OVCITP) consortium to leverage resources for economy of scale. The consortium includes over 130 providers of data and video services in southern Ohio and northern Kentucky. To assess community health information needs, the University of Cincinnati conducted interview and focus group meetings early in 1994. An informal survey was also posted on TriState Online (TSO), greater Cincinnati's Free-Net. The community inquiry provided a list of consumers' expressed health information needs, which was incorporated into the proposal planning process:

- Drug information
- Disease information
- Physician referral and access to experts
- Wellness/general health information
- Alternative therapies information
- Insurance/health planning information
- Professional health literature

The project's objectives were:

- To provide easy, equitable, and widespread access to health-related information resources to the general public in the Ohio Valley region, particularly rural Appalachian and urban minority populations.
- To provide comprehensive training programs for these health information resources by working with community and regional partners.
- To use the existing telecommunications and hardware infrastructure to extend health information resources to as many citizens of the Ohio Valley region as possible.
- To contribute to extending the information superhighway to all citizens of the Ohio Valley region.
- To facilitate health care reform by contributing to the health education and awareness of the Ohio Valley.

System Description

Team-building has been a hallmark of NetWellness from the earliest days of proposal planning. The team approach is prevalent in the content, connectivity, hardware, software, partnerships, public access, training, quality assurance/quality control, and evaluation aspects of the project.

Content

As an "electronic consumer health library," NetWellness collected, and continues to collect, resources selectively. A database acquisition and development team evaluates resources for purchase, for conversion to electronic format, or to assign hypertext links. Common interfaces have been developed for some of the commercial databases, such as Ebsco's Health Source, and also for locally developed information resources, including HOPEline, the Health Professionals Directory, and a planned Directory of Community Services.

Content planners actively sought consumer-oriented materials from community agencies and organizations and their parent organizations. Important pamphlets, especially materials from government agencies and national charitable research organizations and other materials (e.g., American Lung Association, Arthritis Foundation, National Stroke Association), were converted to HyperText Markup Language (HTML) by NetWellness. Selected related information sources on the Internet also were linked to NetWellness.

Hot Topics were developed through the content planning, evaluation, and user feedback processes. Hot Topics respond quickly to evolving, acute public information needs by providing quality information and links. Topic contents may include:

- An "Overview" definition of the topic and its scope of coverage
- "Additional Information," which includes consumer pamphlets and patient education materials provided by leading charitable research organizations or governmental agencies; it also includes links to appropriate institutions/institutional resources
- "Electronic Books and Magazines," which includes Ebsco's Personal Medical Advisor, the Physicians' Desk Reference, the Merck Manual, and Ebsco's Health Source
- "Professional Health Literature," including MEDLINE and five other databases
- "Community Resources" from locally-maintained databases
- "Ask an Expert," currently providing four expert areas (Children's Development and Health, Obstetrics/Gynecology, Pharmacy/Medications, and Pregnancy/Breastfeeding)

Hot Topics can be easily updated and archived for continued use.

Content planning also led to development of "In the News," which nightly indexes four national news services on the WWW. Their contents then become fully searchable on NetWellness for at least a week.

Connectivity

Telephone service options in the original NetWellness service area vary widely. In southern Ohio alone, four major and many smaller local exchange carriers (LECs) divide the region into multiple Local Access Telephone Areas (LATAs). Some rural residents are still without telephone service at all, while many of their neighbors are limited to plain old telephone service (POTS) access to dial tone. Few advanced calling features may be available. The cost of obtaining high-speed telecommunications links across LATAs can be prohibitively expensive; if an LEC physical plant is not up to date, these links may be impossible to implement. Therefore, NetWellness addresses the twin needs of infrastructure development and access. This is done in three ways:

- Users may visit NetWellness resources directly over the Internet, via the WWW protocol. Many resources are available to users in this fashion.
- Users without Internet connectivity but with access to a regional community network (in many cases a Free-Net) such as TriState Online (TSO), may dial in through their network to reach many of the resources, including the Ask an Expert service.²⁸
- Users with no access and no equipment may visit one of 43 public access sites, placed in public libraries, hospital and clinic waiting rooms, senior centers, community centers, pharmacies, and similar locales. One workstation travels with a cancer education and prevention van, using a portable microcomputer and a cellular modem. NetWellness's full suite of resources is accessible from these workstations.

Public access workstations may be connected via an Ethernet backbone, frame relay, integrated services digital network (ISDN), leased line, or dial-up serial-line interface protocol (SLIP) service at 28.8 Kbps. The University of Cincinnati (UC) maintains an Internet segment featuring a 100-Mbps Fiber Distributed Data Interchange (FDDI) backbone, with 10-Mbps copper Ethernet links within the buildings. The NetWellness production servers are connected to this backbone. The UC network connects to the Internet via Ethernet to the Cincinnati point of presence maintained by OARnet (Columbus, OH). Meanwhile, TSO maintains redundant 128-Kbps ISDN links to UC, and it connects to the Internet via its own T1 (1.5 Mbps) service.

Also, TSO supports separate, free, text-only dial-in connections. Public sites in southeastern Ohio connect to NetWellness through the Ohio University College of Osteopathic Medicine's (OU-COM) frame relay network at 64–128 Kbps, through direct Ethernet connections to the OU-COM network, and by dialing in with high-speed modems to a local Internet service provider (ISP). One site connects to NetWellness through a T1 connection to the Ohio Public Library Information Network (OPLIN).

Hardware and Software Platforms

Each public access workstation includes a 90-MHz Pentium processor, a 17-inch monitor, and a printer, all running under the Windows NT operating system. The host site maintains several development and production servers. The development server is a Silicon Graphics (Mountain View, CA) Indy workstation, running the UNIX operating system, and Netscape's Netsite World Wide Web server software. Two Pentium workstations act as production servers; one runs FreeBSD (a UNIX variant) and Netsite, and the other runs Windows NT and Sybase, a relational database management system. A third Pentium workstation running Windows NT serves CD-ROM databases that have been re-hosted onto magnetic disk.

The Windows NT servers communicate with the public access workstations through a native peer-to-peer protocol called the NetBIOS Extended User Interface (NETBEUI). Public access workstation users also reach some remote databases via Telnet software, which provides a text-based interface only. The overall interface is provided through Mosaic browser software obtained from the National Center for Supercomputing Applications (NCSA). With NCSA's approval, NetWellness technical staff have modified Mosaic's source code to allow it to function in a kiosk mode on the public access workstations. This mode provides for the selection, connection, and display of materials, but it reduces opportunities to "break out" to unscripted Web locations. It was necessary before browser developers began to provide a kiosk mode option.

Status Report

Partnership-building

There was tremendous support in the community for the concepts proposed. Community agencies were eager to work together, sharing their services in time, content provision, technical assistance, and training. The OVCITP consortium developed four proposals to NTIA, covering several aspects of universal service and interoperability, community health information,

and community education information. Besides the partnering evidenced by the coordination of the grant proposals, 30 of the initial potential public access sites provided formal expressions of support for the community health information project before the grant proposal was completed. It was this proposal that was accepted and became NetWellness.

Obtaining content and technical resources is a challenge for any information-services project. Most commercial companies were willing to grant an educational discount or arrange other special licensing arrangements. Many were willing to provide assistance in exchange for recognition, the opportunity to test new applications of their product, or the opportunity to investigate new markets. Use of beta-version software was resisted as much as possible.

As mentioned previously, NTIA provided the seed money for NetWellness. NetWellness also proposed a follow-up project to the National Action Plan on Breast Cancer to disseminate breast cancer information. Strong community ties, developed from past project associations, helped draw local legislative support. The legislators proposed and passed state budget allocations, which provided a significant portion of the matching funding and have extended the project's life span.

The TIAP required a 100% funding match from non-federal funds to encourage the formation of partnerships. Because of the short time-frame dictated by the Request for Proposals, many potential partners contacted for matching funds were interested in the project but unable to make a financial commitment to a major project on such short notice. The University of Cincinnati Medical Center helped underwrite the initial pledge match in anticipation of later commercial support. After the grant award was announced in October 1994, many partners became interested in supporting both the technical and content aspects of the project. By May 1995, total non-federal contributions were over 60% of the total budget and now approach 80%.

A project of this size could not succeed without a broad base of support. Individual programmatic themes as well as overall goals have been advanced by identifying areas of particular interest to potential partners. Discussions, based on open and honest assessments of plans and possibilities, and clarification of expectations from all parties have smoothed the management of the project. Documenting all agreements is also important for establishing mutual understandings and responsibilities. Guidelines with a strong service commitment have steered the project from its inception.

Public Access Sites

NetWellness serves 29 counties in southern Ohio, southeastern Indiana, and northern Kentucky. This region includes the Cincinnati–Hamilton Consolidated Metropolitan Statistical Area and the Dayton–Springfield Metropolitan Statistical Area in southwest Ohio. The next-largest city is Athens, Ohio, in the southeast part of the state. In between and adjacent are primarily rural areas of three states, including some of Ohio's poorest counties. For example, Adams County, Ohio, leads the state in unemployment and has the lowest per capita income.

Public workstations are located throughout this region in 13 libraries, 12 clinic/practice centers, 9 hospital clinics, 3 senior centers, 3 public television and community video centers, 2 pharmacies, and 1 cancer education mobile van. Three of the sites are urban public health clinics. One of the senior centers is located in central Cincinnati, adjacent to the downtown area. Ten of the sites are rural hospitals or health clinics.

Training

At each site, a NetWellness trainer is the lead contact, coordinating with site personnel and project technical staff. The trainer arranges installation and training dates. Training is usually scheduled for one to two days after workstations are installed and tested. "Train the trainer" sessions prepare site personnel with the knowledge, skills, and materials to teach other project participants and the general public.

Online "Help" provides assistance and describes each area of the system. Help information is updated regularly as a part of system development and maintenance, and additional context-sensitive help features are being developed. Convenient printed help guides are also given to users at each public site. These include "Basic NetWellness," "NetWellness User's Guide," and "NetWellness Remote Access Guide." Guides are revised and distributed as needed. Trainers can also assist with preparation of local, site-specific documentation and help guides and with local public-relations efforts.

With support from Channel 48, WCET, three training tapes have been produced on videocassette: "NetWellness BASICS," "ADVANCED NetWellness," and "How to Find Information on Diseases and Disorders Using NetWellness." Each public-access site maintains copies for local showings and lendings to the community. The tapes will also be broadcast by Channel 48 and offered for broadcast to other organizations. Also, WCET broadcast a one-time live call-in show on its regional cable channel. Project staff assisted callers

with questions about using NetWellness to find health information. The show was recorded and has been re-broadcast on regional cable outlets on a recurring basis.

Quality Assurance/Quality Control (QA/QC)

NetWellness content is selected, in the same sense that a library selects from among available materials, on the basis of authoritativeness, quality, accessibility (in content level as well as in format), and balance. Particular community interests are considered. Materials proposed for inclusion in NetWellness undergo group review and are referred to outside experts if necessary.

Style guides maintain consistency of look and feel across similar parts of the system. They also provide for reference to past decisions regarding markup, link organization and representation, and other features that aid the "flow" of content, as well as its appearance. The quality-assurance reviews guarantee that common Web maintenance issues such as remote link and content changes are handled quickly and orderly. In Phase 1 of a two-phase QA/QC program, every page of the Web site was reviewed by at least two members of the NetWellness staff. Phase 2 provides continuing quality control by refining the procedures for preparing content, reviewing and maintaining existing content, refining content flow, and maintaining style guide decisions. Off-site links are currently checked manually but will be checked automatically after a pending server software upgrade has been completed.

Procedural checklists aid in workstation installation and troubleshooting. Tasks are organized to ensure smooth preparation, installation, and testing of workstations. Once installed, system troubleshooting includes directly swapping out units with "hot spares." This keeps sites running with minimal interruptions. Units are then tested at the university, and repairs are scheduled. Training contacts, technical staff, and others are kept apprised of problems and resolutions for subsequent informed decision-making.

As noted above, sites have one primary contact for all questions: namely, the trainer, who is a content and public service specialist. Trouble calls and other problems are logged into an online help desk system for follow-up, communication among team members, resolution, and review.

During initial pilot development, both "production" services and development tasks were run from the same computer. As the system has become more production-oriented, the work has been moved to dedicated servers. This helps guarantee that development of new features and subsystems will not disturb day-to-day operations and that users will experience minimal service interruptions.

Next Steps

Evaluation

Quantitative Issues

The stateless nature of communications using the Web makes it difficult to identify and categorize usage. Part of the efficiency of the Web protocol lies in its ability to allow remote clients and host servers to exchange data requests and fulfillments with a minimum of communications overhead. There is no "login" or "logout," and the client and host systems do not have to establish a formal "work session."²⁹ There is further difficulty in interpreting Web transaction data: When does a new session start or end in a hypertext environment?³⁰ In a public setting it is impossible to monitor when one user leaves and another user enters the system. Counting the number of times a particular Web page is viewed is also misleading, since the most-viewed pages are likely to be major branching points and menus. It is difficult to determine what kinds of patterns represent particular uses or user styles. Nevertheless, software products are becoming available that can assist with interpreting Web server log information and help to reconstruct the user's experience at the workstation. In this fashion, the location of requesting clients will be identified, and the duration and flow of work sessions will be estimated.

An online self-selected survey is being presented to users in a further effort to collect individual user information. Users are queried about their information needs, their encounters with the system, and demographics. This data will be compared with transaction log analyses to obtain a picture of how NetWellness resources are being used. Observance studies will not be conducted to preserve personal aspects and to reduce labor costs.

Qualitative Issues

To pursue qualitative evaluation of the project, its designers will rely more on anecdotal evidence and post-experience interviews than on experiential interviews. It is easier to identify or infer "intentions" to change behavior than it is to measure actual changes in behavior. In evaluating information systems success, there are many precursors to "behavioral intention to act,"³¹ and many co-factors operate along with "intention" before behavioral action actually takes place.³²

To evaluate behavioral changes, a baseline picture of the community's health behaviors and health information-seeking behaviors will be needed. Longitudi-

nal focus group and interview studies will provide valuable information about trends. Because they are extremely labor intensive, these studies will be the focus of subsequent efforts.

Continuation

Both commercial and public-sector funding scenarios are being considered for continuing NetWellness beyond June 1997, when the State of Ohio supplement expires (federal funding is slated to end December 31, 1996). Since Ohio has several networking projects underway to link its higher education institutions' libraries ("OhioLINK"), schools ("SchoolNet"), and public libraries (OPLIN), one clear direction is to promote NetWellness as a statewide consumer health information resource. Other funding possibilities call for NetWellness to partner with managed care providers and/or large employers for employee health and wellness education services. As of this writing, all of these scenarios remain viable.

Discussion

An electronic, consumer-oriented health information service, designed to serve a wide range of users, both geographically distributed and socioeconomically diverse, must attend to at least three key elements for success:

- Developing partnerships at every level, from the local community through the state and national levels, both public and private
- Presenting quality content, selected for authority, quality, accessibility, and balance
- Providing easy access for all users, regardless of location or social standing

A firm political underpinning is crucial for achieving economic and technical objectives that serve content goals. Relationships with legislators, built over long associations on other urban and rural outreach services projects, assisted in securing State of Ohio funding. The opportunities to associate with an important public project or to test new markets brought many commercial content and technology providers into the project. OhioLINK assisted in structuring an agreement whereby MEDLINE and other health databases from OVID Technologies (New York, NY) are offered at all NetWellness public sites through telnet connections to the OhioLINK host. Other publishers negotiated licenses to allow "rehosting" of their CD-ROM data in magnetic media for better performance. The library model of resource selection has been effective

in promoting acceptance of NetWellness. It also provided a solid public service base for collection development efforts and creation of new services.

The positive implications of the NetWellness experience will be difficult to realize nationally if barriers that impede universal access to adequate telecommunications service remain in place. While placing public access workstations in disadvantaged areas is one step in "leveling the playing field," even these workstations are bound, by the limitations of the infrastructure, to dial-in modem connections. NetWellness has shown that these connections are only marginally adequate for delivering sophisticated information resources to the health information consumer. State sponsorship of expanded telecommunications infrastructure capabilities will at least mark Ohio's citizens as among the more fortunate over the near term.

While NetWellness claims many successes, not all goals have been met equally. Many desired information resources were simply not available in networkable form. Most commercial resources that could be networked were not Web based, which presented many technical challenges. Many commercial producers of information resources are now adding the WWW to their array of distribution means, giving NetWellness developers hope that NetWellness will be a seamless Web environment.

Other resources were only available under licensing terms that do not reflect the unique environment the Web represents. Traditional database pricing mechanisms assume a "tethered" environment whereby users maintain a one-to-one relationship with a port assignment of a server, or a logical work session in a multiuser operating system environment. Thus, the number of concurrent users can be determined and prices scaled accordingly. For example, NetWellness users' access to OVID Technologies' health databases offered through OhioLINK is limited to ten concurrent telnet sessions. In the Web environment, the user-host encounter is "connectionless"; each query and response is a discrete event, for which no enduring link is established. Many of these stateless transactions can be performed in a short time, yielding a higher level of productivity than before. Therefore, estimated costs based on previous models of system capacity are greatly exaggerated. Instead, NetWellness is exploring future licensing arrangements that will be based on capitation models.

Political and technical issues delayed the implementation of some public sites, reducing opportunities to evaluate their use and impact. Limited facilities in some public sites made training sessions more diffi-

cult to present. Evaluation of Web-based services will likely remain difficult until new methods of measuring use unobtrusively are devised. Further determination of factors that may affect a person's likelihood of using or not using any electronic consumer health library is also needed.

Nevertheless, in a scant 27-month federal grant period, NetWellness will have brought together partnership, content, and access elements in an unprecedented fashion in the region. By blending existing resources and encouraging new alliances, the project has established a model for providing the best health information to the most people in the targeted region.

The authors thank the two anonymous JAMIA reviewers and the editor for their extensive and insightful suggestions.

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NetWellness can be seen at <http://www.netwellness.org>. For additional information, contact the authors or send electronic mail to info@netwellness.org

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