Policy Perspectives

Access to Health Information and Support

A Public Highway or a Private Road?

Thomas R. Eng, VMD, MPH; Andrew Maxfield, PhD; Kevin Patrick, MD, MS; Mary Jo Deering, PhD;
Scott C. Ratzan, MD, MPA, MA; David H. Gustafson, PhD

Information and communication technologies may help reduce health disparities through their potential for promoting health, preventing disease, and supporting clinical care for all. Unfortunately, those who have preventable health problems and lack health insurance coverage are the least likely to have access to such technologies. Barriers to access include cost, geographic location, illiteracy, disability, and factors related to the capacity of people to use these technologies appropriately and effectively. A goal of universal access to health information and support is proposed to augment existing initiatives to improve the health of individuals and the public. Both public- and private-sector stakeholders, particularly government agencies and private corporations, will need to collaboratively reduce the gap between the health information "haves" and "have-nots." This will include supporting health information technology access in homes and public places, developing applications for the growing diversity of users, funding research on access-related issues, ensuring the quality of health information and support, enhancing literacy in health and technology, training health information intermediaries, and integrating the concept of universal access to health information and support into health planning processes.

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INFORMATION and communication technologies have advanced us to a new age as we approach the end of the 20th century. The percentage of US households with personal computers increased from about 8% in 1984 to 41% in 1997.[1,2] In 1985, there were approximately 1000 computers with constant connections to the Internet; there are now more than 4 million.[3] A decade ago, the Internet was used only by relatively few scientists and engineers; in 1997, approximately 41.5 million US adults were active users.[4] The volume of information on the World Wide Web is so vast that even the best search engines have cataloged only about 28% of it.[5]

Much of the information on the Internet is health related, and researching health information is one of the most popular reasons for using the Internet. In 1997, nearly half of US users spent some time looking for health information or support on the Internet.[6]

The Internet is clearly an increasingly powerful channel for interactive health communication[7]—the "next wave" of health communication that enables tailoring of information based on an individual's level of literacy, method and point of access, health status, and psychosocial variables.[8,9] These technologies can help promote self-care and healthy behaviors and provide access to peer and emotional support given specific needs. Better-informed decisions may be a principal benefit, but as a result, there also may be more appropriate demand for health care services, leading to both improved health status and reduced total costs of illness.[10,11]

For those with access, health information is more readily available than at any time in history. Answers to nearly any health question are available at any time. The implications of this phenomenon extend to the traditional health system because the growth of the Internet and its ability to support people in making informed health decisions may amplify another trend, the decentralization and democratization of knowledge about medicine and health from traditional health professionals to others.[12] This trend stems from several factors: (1) patients are increasingly interested in participating in clinical decisions; (2) advances in biomedical and public health knowledge have become so rapid, voluminous, and complex that no single clinician can keep up with all of it; (3) efforts to contain costs are limiting clinicians' ability to spend time with patients; (4) health plans and employers are promoting self-care and prevention; (5) the aging of the US population is increasing the demand for health information and support; and (6) people are increasingly interested in alternative health care approaches.

Who Will Have Access?

There is an open question about the limits of diffusion of this technology: will everyone benefit from the increased availability of online health resources or are we headed toward a society of information "haves" and "have-nots"?

Although American society seems to tolerate unequal access to health care, we now have a window of opportunity to avert a similar inequity in access to health information and support. Currently, those who are most likely to have health

problems and lack health insurance coverage are least likely to have access to the Internet or have the skills to use it. However, these populations can benefit greatly from health information and support.[13] While higher socioeconomic status (SES) households typically have access to both health care services and online resources, the estimated number of uninsured Americans increased from 31.0 million (12.9%) in 1987 to 41.7 million (15.6%) in 1996.[14] Lower-SES and rural households and African American and Hispanic persons are less likely to own a computer or have Internet access than other groups.[15] In January 1998, 38% of US households with incomes of $50 000 or more had Internet access compared with only 7% of households with incomes less than $20 000 (Mark Nelson, ZD Market Intelligence, Technology User Profile, written communication, July 1998).

The reasons why online health resources are less accessible to some groups in the United States mirror the issues that have confronted health care for decades: cost, geographic barriers, literacy, culture, disability, and other factors related to the capacity of people to use services appropriately and effectively. More broadly, one set of barriers is related to the infrastructure and hardware necessary for accessing these technologies; the other is associated with the characteristics of nonusers and the information and applications themselves.

Currently, the most common platform for accessing online resources is through personal computers. Although their prices have dropped substantially in recent years, even computers that cost less than $500 and monthly online service charges are not affordable to many. In addition, residents of rural and lower-SES areas have fewer telecommunications services than people in cities.[16] For example, the market for Internet service providers is centered in highly populated and generally wealthy urban areas.[3]

Lack of access to infrastructure and hardware, however, is only part of the problem. Certain populations also have difficulty accessing online health resources because the content or the medium of the application is inappropriate for them. This may be because they have inadequate technology or literacy skills, cannot understand or use health information, have a physical disability, or cannot communicate in English.[17-21] Many of these factors also are substantial barriers among higher-income families.[17-22] Although only about half of the US population has rudimentary or limited reading skills,[22] most health Web sites are primarily text based and are designed for educated, literate, and nondisabled audiences. Technologies that improve usability and access, such as television-based Internet, voice recognition, and touch screen systems, are only beginning to emerge.

Is Enhancing Access Among the Underserved an Appropriate Goal?

From a social equity perspective, the value of enhancing access to online health resources among the underserved is self-evident. However, there are several valid questions regarding the potential workability and impact of this goal.

Can the underserved use technology? Studies show that when barriers to technology access are addressed and training is provided, underserved populations, including low-income families,[23-27] residents of inner cities, housing projects, and rural areas,[28,29] disabled persons,[30] the elderly,[31] racial and ethnic groups,[32,33] and drug users,[34,35] can successfully use technology to address health concerns.

Do the underserved want access? People desire and seek health information and support from a variety of sources,[36,37] and many underserved groups are keenly interested in using technology, including the Internet.[16] In 1 survey, almost twice as many African American persons as white persons planned to purchase a computer within the next 6 months.[38] Another survey suggests that the elderly and the disabled want and may use health information and support resources more than others.[37] In addition, when a home computer and Internet access were made available, lower-income families became enthusiastic users.[27]

Does access improve the health of the underserved? Health information and support are critical to health promotion efforts among the underserved.[39-41] Some benefits of interactive health communication have been documented among the general population,[7,10] but data on its direct effects among underserved populations are limited. Some studies suggest that these tools can improve health knowledge, attitudes, and cognitive functioning[33,42]; enhance emotional well-being[43]; and reduce use of health care services without affecting health.[33,35]

Will the underserved be harmed by access? Some may argue that improving access to online resources, some of which are inaccurate or inappropriate, might harm the underserved. Although the underserved may be less health literate and less educated about judging the quality of information than others, this does not necessarily mean that they are unable or unwilling to systematically process information in making appropriate health-related decisions. Low-income consumers are capable of resisting persuasive marketing communications.[44] One national survey showed that Americans with annual incomes of less than $15 000 wanted independent information more than any other income group when purchasing a range of products, including health insurance and prescription drugs.[45] This suggests that underserved populations, when confronted with important health-related decisions, will seek independent information and critically evaluate information. Because large volumes of high-quality resources that are relevant for all populations already exist (see http://www.healthfinder .gov),[46] there is little justification for delaying access to them. Of course, because some people, rich and poor, may be harmed by inaccurate or inappropriate information, the quality of online resources must be improved and training users in selecting and using such resources should be a priority.[7]

Is investing in access an appropriate use of limited resources? The issue is not choosing between access to health care services and health information—both are clearly essential. As health care services are increasingly being shifted from health care settings to the home and community,[47] access to the tools of health communication will become a prerequisite to obtaining health services. In addition, enhancing access to health information and support may promote more efficient use of services,[48,49] reduce the total costs of illness,[11] and help avert preventable health conditions that disproportionately affect lower-SES populations.

Universal Access to Health Information and Support

We propose a goal of universal access to health information and support to augment existing national health initiatives. The fullest realization of this goal might be that everyone has access to the Internet at home and knows how to use it to improve their health. However, individuals do not have to possess the technology to have access. Short of this goal, com-

Access to Health Information and Support—Eng et al

puters and other information appliances could be loaned or provided at reduced cost to people in need. More immediately, networks of public access points could be developed.[50,51]

In 1997, approximately 60% of public library systems offered some form of public access to the Internet and nearly every library will offer this service by the year 2000.[52] Providing access through libraries is a good model, and there is little reason why other public facilities cannot support public access terminals or kiosks.[50] For the near term, until such time that home access is universally available and affordable, universal access may necessitate a combination of private (ie, home) and public (eg, schools, libraries, public buildings, post offices, shopping malls, community centers, health care facilities, places of worship) access points. Universal access, therefore, could be defined more broadly as the ability to locate, comprehend, and use health information and support appropriate to one's personal characteristics. Because the need for health information and support is often unpredictable and acute, the definition should also include availability within a reasonable period and travel distance.

The arguments for a social goal of universal access to health information and support include the following:

Public Information.—The great volume of health knowledge generated by public funds either directly (ie, by government grants or agencies) or indirectly (ie, by government grants to the private sector) should be freely accessible and available to all. Approximately 80% of basic biomedical research in the United States is supported by federal funds.[53]

Public Health.—Enhancing access to appropriate information and support improves the quality of individual health-related decisions and supports public health goals. Making health information available is an essential public health function,[54] and information and support are critical links in a chain of supporting factors that are necessary for adoption of healthy behaviors and disease prevention.[55]

Cost Savings.—Improved access to information and support resources may lead to better clinical decisions and more responsible and efficient use of limited health care resources.[10,56] This, in turn, may help reduce the current strain on social safety nets and reduce health care costs.

Universal access to online resources is in many ways analogous to the original intent for the public library system and extension services of public agencies and universities. Their goal was to further the public good by making information and support freely available to all, thereby encouraging an informed citizenry and a vibrant democracy. There is a remarkable egalitarian quality to the library system and extension services as institutions, and the same quality is shared, and perhaps enhanced, on the Internet. Posted information is available to anyone with access, at any time, and at relatively low cost. There seems to be community consensus that public access to books, periodicals, and professional advice and support is an appropriate use of public funds. Why not access to the Internet? Instead of a local library or extension agent, we now have a virtual resource center that is global in scope.

The costs associated with ensuring universal access to health information and support are significant barriers. Infrastructure costs include related hardware (eg, communication lines, routers, servers, modems) and interfaces with users (eg, computers, kiosks, television-based Internet, and personal communication devices). Other costs include training both for information intermediaries (eg, health professionals, librar-

ians, educators) and users and for development of interfaces that are suitable for diverse audiences.

Much of the infrastructure to deliver interactive media to the home may already exist. Advances in communication technology promise high-speed Internet access through various channels, such as existing telephone lines (eg, integrated services digital network, digital subscriber line), coaxial cable (eg, cable modems), and wireless transmission (eg, satellite, microwave). The costs of computers and communication services are rapidly declining and the promise of converging information appliances may make home access more affordable. In addition, the cost of providing universal access to health-related resources may be lower than expected because the infrastructure for such access can be shared among social, educational, and community services.[57]

Finally, the replication of health information on the Internet has little to no variable cost. The same is not true for health care services where unit costs are relatively fixed. Once information or an application is developed and published on the Internet, there is little to no marginal cost for additional persons to use them. In contrast with providing access to health care, the value derived from Internet-accessible resources is virtually cost free.[58]

Building a Public Highway

Providing universal access will be a major undertaking and will require both public- and private-sector funding and partnerships. Such an initiative will need to be a multidisciplinary effort, with coordination and collaboration among a wide variety of stakeholders on a local, regional, national, and perhaps international level.[59,60] There also is a need to develop business models and return-on-investment analyses to encourage corporations and developers of online resources to target underserved populations. Potential mechanisms for supporting universal access include the following:

As a Component of Private-Sector Health Services.—Some health plans and employers are providing access to online resources that promote healthy behaviors and self-care.[61-63] Some already share their resources with the public while offering additional features for their members or employees. Promoting preventive services and lifestyle changes among beneficiaries and employees can improve worker productivity and reduce health care costs[64] and may also enhance the quality of clinical services and attract or retain plan members.

As a Component of Federal- and State-Funded Health Programs.—Medicaid and Medicare managed care organizations and agencies may find that improving access to health information and support may improve health status and reduce health care costs among populations typically at high risk for many diseases. By 2020, 15% of the US population will be 65 years of age or older. This segment of the population traditionally consumes more health care resources than any other[65] and these people are acutely interested in self-care.[66] By providing resources that improve self-management of chronic conditions and facilitate shared decision making and peer and emotional support, government agencies, Medicaid, and Medicare managed care plans may benefit from the more efficient use of services.

As a Requirement of Federal Grant Programs.—Federal agencies may consider requiring grant recipients to incorporate enhancements to information technology infrastructure as a component of appropriate federally funded programs and

activities. In addition, grant processes that require inclusion of underrepresented and underserved populations in research protocols could be modified to ensure that all groups are included in information technology research.

As a Strategy for Public-Sector Agencies and Charitable Organizations.—As more public-sector health services shift to the private sector, private charitable organizations can fill gaps in community services, including information and support functions. Information technologies may help expand the reach of such services.

As a Strategy for Corporate Marketing.—Pharmaceutical companies and other health care companies have an incentive to promote health literacy and ensure that information about the health conditions in which they have an interest are widely available and accurate. Providing appropriate, unbiased information and support to consumers and health care providers such as hospitals, clinicians, and insurers may improve the quality of clinical decisions and potentially increase consumer demand for cost-effective medications and procedures.

As a Portion of Private and Public Long-term Investment in Communities.—Technology companies and other corporations may find that providing or subsidizing computer equipment, skills training, or interactive health communication applications to lower-SES groups may improve community relations, increase company recognition, develop new markets for their products, and increase the potential pool of skilled workers in the region. Nonprofit organizations and small businesses can become involved by donating used equipment, sponsoring public workshops, and providing trainers to community groups. In addition, the Telecommunications Act of 1996 provided support for improved access to advanced telecommunications by authorizing universal service discounts to kindergarten through 12th grade schools, libraries, and rural health care and public health facilities, but full implementation of the program is uncertain.[67]

Public- and private-sector grants and other incentives are critical to promoting the development of online health resources that recognize the growing diversity of potential users and to support basic and applied research on access-related issues. As the volume of health information proliferates, mechanisms for ensuring the quality of such information must be developed.[7,68-72] In addition, health and technology literacy programs that educate the public about use of technology and how to understand, interpret, and evaluate health information should be coupled with initiatives to improve infrastructure. Additional training for health information intermediaries will be needed to enhance their role in improving health and technology literacy. Finally, the notion of universal access to health information and support should be integrated into international, national, state, and local health planning processes to improve access to both health services and health information and support. Integration of this concept into national health planning processes such as *Healthy People 2010* can serve as a prototype.[73]

In the next decades, we have the unparalleled opportunity to apply new and emerging technologies to achieve equity in health information access and build on health initiatives for the 21st century.[74] Technology, if used appropriately, can help people increase their knowledge of health, enhance their ability to negotiate the health care system, understand and modify their health risk behaviors, and acquire coping skills and social support. Furthermore, by reducing the information divide now, the next century may bring us closer to health equity.

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Access to Health Information and Support—Eng et al

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