Assessment of the Digital Divide:
Barrier to Health Communication Dissemination

by

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April 11, 2006

A Master's paper submitted to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Master of Public Health in the School of Public Health, Public Health Leadership Program.

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Abstract
In 1984 the U.S. Department of Health and Human Services reports that while there is progress in improving the overall health of the general public, there is evidence of significant disparities in the overall health of selected racial minority groups. Empirical evidence supports that "socioenvironment" is a primary determinant of individual health outcomes and is a factor in the health outcomes for these targeted groups. Subsequent epidemiologic studies link access and substandard health care as prevalent in poor and minority communities. Federal, philanthropic, and advocacy organizations responded by organizing to eliminate racial and ethnic disparities in the U.S. One tool that has gained widespread attention is the expansion of the Internet as a tool for communication of health information to improve overall health outcomes. Research shows that characteristically, groups experiencing the greatest health care disparities are the same as those without access to computers and Internet services. Projects to reduce this trend are currently being piloted and are showing progress in confronting this problem.
Empirical evidence abounds on the differential health status for specific racial and ethnic populations. This reality prompted the Institute of Medicine (IOM) to publish a report “Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care” as one approach to open dialogue on the topic with the intent to generate strategies for its elimination. The IOM committee (2000), Understanding and Eliminating Racial and Ethnic Disparities in Health Care was created to define and offer recommendations on reduction or elimination of health care disparities in the U.S. The committee was charged to investigate and identify “potential sources of racial and ethnic disparities in health status not attributable to access, income, and/or insurance coverage” (Smedley et al., 2003). The Committee’s goal was to provide recommendations for interventions that would eliminate overall health care disparities in the United States.

The IOM report describes a correlation between “health disparities” and a new concept “digital disparities”. Digital disparities is a term that defines racial and ethnic groups with low Internet access usage and those groups that neither have nor desire access to the Web. The IOM report highlighted a list of determinants of current health disparities for specific racial and ethnic groups citing communication within and across specific groups as one potential factor. Other health determinants for the poor, minorities, and some ethnic groups are culture, behavior, substandard care/medical errors, and overall quality of care received. Political and social leaders subscribe to the premise that limited individual and family resources are a primary barrier to effective use of health information, communication, and support for reaching vulnerable populations.
The Digital Divide

The Digital Divide is most commonly defined as the gap between those individuals and communities that have, and do not have, access to the same information technologies that are having a significant impact on how Americans live (National Academies Press, 2003). The U.S. Department of Commerce Digital Divide Summit in 1999 documented the potential serious health consequences for communities left out of the digital age and while there is an increasing reliance by U.S. families on these technologies (The George Lucas Foundations, 1999). Individuals and communities on the outside are described as being members of America’s digital divide. Eng (2004) warned that digital disparities in online access could leave a large portion of American society outside the “cutting edge innovations in population health technologies”. This differential suggests that many with the greatest need for health promotion and disease prevention information will not benefit from information updates on “disease surveillance, environmental monitoring, food safety, emergency planning, disaster management, and geographic information systems based tracking of environmental hazards” accessible to other groups.

The U.S. Department of Commerce in 1999 in “Falling Through the Net” reported that there exists a serious divide between individuals and groups that have access to “new information technologies and those without”. The report suggests that rather than narrowing, the gap for these groups is widening (NTIA, Department of Commerce, 1999). In 2003, a follow-up survey by the Department of Commerce survey (Horrigan et.al. 2003), new evidence suggests that African-Americans and Hispanics with
equivalent incomes to other groups, are less likely to use the Internet. Other sources report that nonusers (52%) cited reasons that include “computer costs and Internet access, fear of fraud, credit card theft” as reasons for never going on-line (Pew/Internet, 2005). In general, factors contributing to low dependence of the Internet for information may include geographic region, literacy, disability, local infrastructure requirements, and cultural difference (NTIA, Department of Commerce, 1999). Spooner and Rainie (2005) offer some insight into behavioral patterns for African-Americans Internet users. Investigators suggest that Internet use for members focus mostly on life style issues, jobs, and religious and spiritual connection, and health information.

*Healthy People 2010: Health Communication*

The IOM defines health communication as “the use of communication to inform and influence individual and community decisions that enhance health”. The IOM links communication and health information as useful tools for improving personal and public health. Healthy People 2010: Health Communication (Focus 11) describes opportunities for making strides in health promotion and disease prevention through dissemination of health information via the Internet. The pathways include: 1) improvements in health professional-patient relations, (2) individual self-search and use of health information, (3) compliance with clinical recommendations and regimens, (4) the construction and dissemination of public health messages and campaigns, (7) and the education of consumers on how to gain access to the media and the culture at large.

The purpose for Healthy People 2010 is to improve the health of the nation. Healthy People 2010 goals are to increase quality of life and individual longevity and to eliminate existing health disparities. The initiative has 467 objectives and 28 focus areas to achieve.
Collectively, they are a response to indicators of disease, trends, and health markers in 2000 that provide target improvement by 2010. A performance plan to monitor progress toward satisfying all goals and objectives and benchmarks of excellence established.

*Healthy People 2020: Focus 11- Health Communication*

There is an elevated awareness about trends happening in health communication in 2006. Consumer communication options include e-mail, print, telephone, and, increasingly, the Internet. Surprisingly, there is little evidence of increased competition for the consumer’s attention to specific issues in health care. An example of competition is best recognized in the direct-to-consumer advertising for prescription drugs. Lack of competition may be one barrier to the expansion of mass media health promotion campaigns. Healthy People 2010: Focus 11 promotes the idea that health promotion and communication campaigns should use audience-centered formats for reaching target groups. This concept is important when applied to racial and ethnic populations. Research suggests that these groups have differing languages and sources for finding information than the general populous and the audience-centered processes involve understanding unique cultural characteristics, types of media access, and terms and styles for communication (IOM, 2000).

Computers and the Internet provide an infrastructure that facilitates access to health information and health-related support services. Internet is providing health professionals with interactive approaches for health professionals to reach patients, consumer, and communities. Compared to traditional face-to-face delivery, the Internet for communication between health professional and patients and consumers offers several advantages. They include:
1. Improved access to personalized health information;

2. Access to health information, support, and services on demand;

3. Enhanced ability to distribute materials widely and update content or functions rapidly;

4. “Just-in-time” expert decisions support;

5. And, more choices for consumers.

While the many unique advantages of the Internet with decision making, receiving support, and promotion of self-care as examples, there are challenges to widespread use. Two concerns are described in the Healthy People 2010 report. First, risks of consumers’ finding inaccurate or poor quality health information on which decisions are based. There is increasing concern that information is often misleading, inappropriate, and may put consumers at risk. Information taken from the Internet can undermine informed decision-making. These concerns have preempted a need to develop a quality standard agenda to aid health care professionals and consumers in locating reliable Web sites and useful health information. The U.S. Department of Health and Human Services describes high quality information as “accurate, current, valid, appropriate, intelligible, and free of bias” Second, use of the Internet as a communication channel creates a challenge to the protection of privacy and confidentiality of personal information. Policies and procedures to protect privacy while maintaining reasonable access to personal information need to be established (Eng, T, 1999).

“The Missing Link: Bridging the Patient-Provider Health Information Gap”, Tang and Lanksy (2005) concur that information technology is a smart choice and practical application to improve health care and achieve the IOM goal to overhaul health
care in the U.S. Highlighted is the need to provide tools to assist patients in becoming more active partners in their personal care. Increased use of personal health records (PHRs) is one tool that might enhance patients and providers communication and transform the health care delivery system towards consumer-driven care. The authors link success to strengthened federal policies on PHR development and adoption. The authors correlate the IOM goal to enhance “safe, effective, patient-centered, timely, efficient, and equitable health care” to the PHR. While the development of the PHR allows patients to access and share health care information, the system is difficult to achieve without a “higher degree of PHR adoption and interoperability throughout U.S. society”. In 2005, approximately 1 percent of the U.S. population was connected to a PHR (Tang & Lanksy, 2005).

Connecting Health Disparities and Internet Implications

The most unhealthy people in the U.S. “have the least access to health information; health related technologies, health care, and supporting social services” (IOM). The many opportunities and advantages of the Internet for mass-delivery of health promotion information, even those well conceived and written in intelligible language, will have limited impact if the target communities lack access to health care providers, services, and eCommunication options. Freimuth (1990) reports that beneficial outcomes for targeted health communication interventions programs, low-education and low-income groups showed fewer changes in unhealthy practices and seemed less informed than higher income and better educated groups. Freimuth suggests that the digital divide is one barrier to the amount and breadth of information that can be made available to mass markets. The use of electronic resources for finding health information
requires sophisticated skills and equipment, weaknesses found in groups experience the highest health disparities. Healthy People 2010 notes that “equitably distributed health communication resources and skills, and a robust communication infrastructure can contribute to the closing of the digital divide and the overarching goals of Healthy People 2010 to eliminate health disparities.

*Digital Government and Public Health*

Elimination of health issues among low-income populations has traditionally been a priority of public health. Disparities in access are typically linked to education level, income, and involvement in political activism (Freimuth, 1990). While there is evidence of progress in computer access and use in most racial and ethnic groups, there continues a lack of computer literacy further exacerbating the digital divide. Jane Fountain’s commentary *Digital Government and Public Health* (2004) describes government’s increasing role in the delivery of health information to the public. She described “digital government or virtual government” in her article in *Preventing Chronic Disease: Public Health Research, Practice, and Policy* as “the production and delivery of information and services inside government and between government and the public using a range of information and communication technologies”. Two types of government interactivity are described: (1) government-to-citizen and (2) government-to-government. She describes opportunities and challenges for both. Challenges to public health agencies are “inadequate funding for infrastructure, expertise, privacy and security issues, and lack of Internet access for low-income and marginalized populations”. Fountain describes limitations to the effectiveness of digital government is the nature of a bureaucratic state. Solutions include creation of new, integrated programs and changes in operating
Barriers to changes include, Fountain suggests, include "limited resources, insufficient funding for technology and infrastructure, determination of the types of technology that enhance most critical to its mission". When technology decisions are to be made, individuals, groups, and agencies consulted may include public health managers, staff, customers, and IT specialists. Additionally, Fountain proposes that technology has the potential for individuals, groups, and communities to groom government using new paradigms. One expectation is that through increased access to government online information and support systems, an enhanced interest and understanding of information and an increase in political activism may occur. Much like social capital is important to communities, it can benefit public health as digital communication expands.

**Digital Divide Pilot Projects: Closing the Gap**

Gary Kreps (2005) offers insight in his article "Disseminating Relevant Health Information to Underserved Audiences: Implications of the Digital Divide Pilot Projects" (DDPP). The DDPPs are programs designed to address the reality of what a White House report correlates as "the link between individuals and groups with health disparities and those caught in the digital divide". The report suggests that the gap between individuals with access to pertinent health information rather than narrowing is increasing. Consequently, the vast storehouse of information that might be beneficial for these individuals is inaccessible. The purpose of the DDPPs are "to make access to computers and the Internet as universal as access to the telephone is today" according to Krep. Further, these projects align closely with Health People 2010 goal which, for the first time, includes health communication as a potential tool and pathway to improving
access, interactive communication, and “computer-mediated health information” delivery.

Starting in 2001 the National Cancer Institute (NCI) awarded nearly $1 million for the development of demonstration research programs to assess strategies for narrowing the digital divide (Kreps et al., 2004). One goal for projects associated with the program was “to identify implications for developing health communication strategies that libraries might adopt to provide digital health information to vulnerable populations”. One assumption is that the digital divide “limits access to and use of relevant cancer information among underserved populations (Kreps et al. 2004). The awards form the NCI’s Cancer Information Service (CIS) proposed to pilot new strategies for collaborations among cancer control groups and organizations for dissemination of health information. CIS involvement provides an opportunity to test approaches to improve outreach to diverse and underserved groups perceived to be in need of health information and support (Krep, 2005). Four projects were selected for funding: (1) the Computerized Health Education and Support System (CHESS) project, (2) the Harlem Project, (3) the Low-Literacy User Cancer Information Interface (LUCI) Project, and (4) the Head Start Project.

*The Computerized Health Education and Support System (CHESS).* The CHESS project is a collaboration between a University of Wisconsin research group and two CSI offices, one in Wisconsin and the second in Detroit, Michigan. The design involved a multiyear health information distribution initiative and to pilot a new dissemination strategy to provide underserved, newly diagnosed cancer patients with access to an Internet-based version of the CHESS system, provide high-quality breast cancer
information and to offer individual support. NCI and other information agencies expected to gain a better understanding of how to disseminate cancer information while reducing the digital divide among cancer patients. Unlike previous studies that requires CHESS information be installed on respondent computers, the new format used the Internet for distribution to new markets in distant geographic regions. Similar to previous outcome measures, the positive effects of previous CHESS projects, this project showed that users were satisfied having positive effects on well-being, support, and adjustment to living with cancer (Kreps, 2005). These positive findings were true for both sets of participants. Michigan respondents were primarily inner-city African-Americans while those in Wisconsin were primarily Whites living in rural areas.

The New York regional CIS/Memorial Sloan-Kettering Cancer Research Center Project. This project in New York City is designed to build a community partnership intervention program for individuals in Harlem. The project aims to inform both consumers and providers on how to access cancer information via the Internet. In preparation, workshops were provided to target populations of lower-income minority (mostly African-American and Hispanic) who belonged to a network of community organizations with links to both technology access sites and training centers. Participants were taught strategies for health information access online. Culturally sensitive Websites were developed for both health care providers and consumers to enhance the quality of the information provided. Study results demonstrated how the efforts of community interventions coordinated by community, government, and commercial organizations can reduce the levels of the digital divide in underserved areas. The project demonstrates that these medically underserved populations would have access to
information with similar quality to the rest of the population. Another benefit is the opportunity to develop and evaluate alternative tools for bridging the digital divide. One example is the CancerInfoNet.org Website that was developed as a part of this project.

*The Low-Literacy Use Cancer Information Interface (LUCI) Project.* The LUCI was spearheaded by researchers at the Louisiana State University Medical School in collaboration with the mid-south regional CIS office. The multidimensional strategy to reduce the digital divide for low-literacy seniors in Louisiana collaborated with senior centers to implement a train-the-trainer program. The project includes a computer education program, computers and Internet for state-operated senior centers, and narrative-based, computerized multimedia information translation application (interface) for improved dissemination of cancer information. LUCI uses multimedia libraries to address literacy-based barriers to computer use and information acquisition. Using a television soap opera format, information is delivered without the need for reading or computer literacy.

Results suggest that the LUCI innovation is popular as it is easy for seniors' to use. Yet, outcome measures do not support significant levels of health promotion knowledge and activity among seniors. While the short-term measures were not as hoped, with refinements of structure and processes, locations for application, and appropriate media, the innovation has significant merit (Kreps 2004).

The Head Start project provides low-income families in New England with health information access. The collaboration between the CIS office of New England and research from Yale University created intervention projects in community technology centers at two Head Start early childhood education programs in New Haven,
Connecticut. The project includes training for Head Start staff to become coaches that deliver computer-training course to parents and community members. Participants who complete the training program are provided free, refurbished, Internet-ready computers for home use. The multigenerational approach involves all members of the family unit. Results suggest a high acceptance of the program along with a positive impact on computer skills, information access, and data utilization. The conclusions support the development of similar programs in Head Start programs in other communities.

Cumulatively, there are several recommendations that can be discerned from each project. They are:

- The Chess project provided evidence that Internet-based health information disseminations to underserved urban and rural breast cancer patients are one cost-effective system.
- The Internet was effective for information dissemination, training, research, and gathering of information and response to client support needs.
- The CHESS programs benefited from innovative collaborations with public agencies such as Medicaid, enhancing opportunities to reach to reach and serve larger portions of low-income populations.
- Collaborations with hospitals, public health agencies, and programs with a goal of reaching low-income patients serve as an effective recruitment tool.
- Outcomes support further investigations to determine which aspects of CHESS help individuals make better decisions of approaches to care.
- Elements of all projects or expanded versions are in place today.
As a result of the LUCI digital divide project, many senior citizen centers have purchased additional computers and establish Internet access at Louisiana locations.

Chang et al. takes these ideas further by establishing a framework for examining information in vulnerable, underserved populations. The framework centers on a vision of the "Ideal State" of informatics for vulnerable populations. The vision is that "all people in America, regardless of literacy level, culture, functionality, or socioeconomic status, will be able to effectively use and act on health information and consumer-oriented e-health tools" (Chang et al. 2004). In his article published in the Journal of the American Medical Information Association (2004), he describes barriers to reaching vulnerable populations and recommendations for policies to informatics to underserved populations. Barriers are framed using six categories for actions.

**Community factors.** Community factors include community perceptions of need for both information and the various information tools. Failure to include major stakeholders in neither community decision making nor incentives to be participants are possible factors. Community members may not understand the value of e-health applications and may mistrust health care providers, health care institutions, and technology.

**Consumer Literacy.** While there is little evidence about the relationship between health literacy and health, the Council on Scientific Affairs, American Medical Association identified four issues: (1) literacy screening and measurement; (2) methods of health education including those that are computerized; (3) costs and
outcomes of poor literacy; and (4) understanding association between health literacy and health (Health Literacy: Report of the Council on Scientific Affairs #21 ref).

**Developer Knowledge.** The needs and cultural norms of a community may not be adequately understood by the developers of health information materials. Issues that include levels of diversity within individual communities and lack of skills by developers to translate messages so they can be understood are potential problems.

Creation of standard and uniform delivery systems is problematic.

**Field Maturity.** Community health informatics is an evolving science. Currently, scientific reasoning for effective delivery of information to underserved groups is ambiguous. There is limited evidence that outcome of information interventions works. Research in these areas is needed to insure proper mechanisms are used to disseminate information and that those mechanisms match community environments, beliefs, and perceptions.

**Financial Incentives.** There is little money available to support development of health information and consumer e-health tools for the underserved. In addition to few resources for research and development, providers often are left without a reimbursement structure for facilitating use of technology by patients. Further, development of partnerships for programs is a continuing barrier to promotion of informatics for these populations.

**Professional Education.** Information topics that include health communication, health literacy, and cultural competence are not the norm for informaticians. Accordingly, disciplines such as public health, medicine, and health behavior may fall short for having relevant consumer health informatics competencies.
Conclusions

Eng et al. (1999) reported that information and technology may be an effective tool for “promoting health, preventing disease, and supporting clinical care for all”. The uninsured are one group with a high incidence of preventable health problems are caught in the digital divide. Barriers to going online include “cost, geographic location, illiteracy, disability, and capacity of people to use technologies appropriately and effectively”.

If health communication and support are to be an effective tool for improving overall health, it is important that both public and private stakeholders, government entities, and corporations work together to bridge the current gap between those with health information access and those left out. Increases in access from homes and public facilities, training for the user, multifaceted funding opportunities on Internet availability, education, and an understanding by the public that access to health information and active participation are components of health care delivery. Evidence cited in the literature as possible solutions for bridging the digital divide to improve overall health focus on primary areas for action that include:

- Adoption of information technology as a health promotion and prevention policy that can lead to improved health care should be promoted to health policy activist for increased emphasis.
- Send a clear message that health information and all tools to access learning materials allow the individual to become an active partner in their personal care; this bridge requires changes in current U.S. health policy that supports standards for improving accessibility to health information.
that is appropriate to age, culture and language and fund research to investigate the benefit of informatics to underserved populations.

- Provide funding to encourage partnerships and collaborations to create and disseminate health information to the underserved and disenfranchised.

- Determine which information formats and systems work best for the various target audiences. A centralized database may be created on project outcomes, educational materials, and funding for similar projects for public access.

- Provide education and training for the intended target audiences.

Specifically, priority should be made to increase content related to evaluation methods for the underserved.

Consumers are increasingly taking greater responsibility for their personal health care. Consumers face important decisions about services, provider of choice, support systems, and treatment options. Information to make the best decisions should be accessible and accurate. Appropriate communication links between public health agencies, providers, and patient are keys to successful health promotion and disease prevention campaigns. Comprehensive delivery of information to all people requires that an elimination of America’s digital divide must be addressed to ensure that everyone is allowed to participate in this evolving health communication and dissemination trend. Universal targets identified in the IOM Healthy People 2010 to improve the health of the nation may be enhanced with improved public health communication systems with access for all.
References


