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# Disseminating relevant health information to underserved audiences: implications of the Digital Divide Pilot Projects\*

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**Objective:** This paper examines the influence of the digital divide on disparities in health outcomes for vulnerable populations, identifying implications for medical and public libraries.

**Method:** The paper describes the results of the Digital Divide Pilot Projects demonstration research programs funded by the National Cancer Institute to test new strategies for disseminating relevant health information to underserved and at-risk audiences.

**Results:** The Digital Divide Pilot Projects field-tested innovative systemic strategies for helping underserved populations access and utilize relevant health information to make informed health-related decisions about seeking appropriate health care and support, resisting avoidable and significant health risks, and promoting their own health.

**Implications:** The paper builds on the Digital Divide Pilot Projects by identifying implications for developing health communication strategies that libraries can adopt to provide digital health information to vulnerable populations.

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Many of the people who are most at risk of poor health outcomes from cancer and other serious health problems are members of underserved populations, populations that are generally made up of individuals who are of low socioeconomic status, possess low levels of health literacy, are elderly, are members of marginalized ethnic and minority groups, or have limited formal education. These underserved and vulnerable populations often have limited access to relevant health information, especially information widely available over the Internet [1]. These same vulnerable populations are also subject to serious disparities in health care and generally have much higher rates of morbidity and mortality due to serious health threats, especially from cancers, than the rest of the public [2]. New strategies and policies need to be developed to help underserved and vulnerable populations access relevant health information and to help them use such information to make informed health-related decisions

about seeking appropriate health care and support, resisting avoidable and significant health risks, and promoting their own health [3].

Health information is essential in health care and health promotion, because it provides both direction and rationale for guiding strategic health behaviors, treatments, and decisions [4]. The digital divide has been identified as a special problem in health care that can lead to significant disparities in care. Many studies show that certain minority groups and low-income, low-education populations in the United States suffer a disproportionate cancer burden and have limited access to electronic information about health [2]. However, too little is known about different disenfranchised groups' interests in, access to, and abilities to use health information.

The US Department of Commerce and other groups have documented the digital divide that separates those who have access to computer technology and the vast storehouse of information available through the Web from those who lack access [5]. A White House report indicates that the gap between people who have access to the latest Information Age tools and those

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who do not is widening, and the digital divide is growing along racial and ethnic lines [6]. This White House report suggested several steps they intended to take to break down the digital divide. One of their goals was to make access to computers and the Internet as universal as access to the telephone is today. The *Healthy People 2010* report for the first time has a section on health communications, with goals for access to health communication and computer-mediated health information [7].

The digital divide is a special problem in health care. Many of the characteristics that identify those on the "have not" side of the digital divide also apply to those who suffer the negative effects of health disparities (e.g., people with less education, with low income, and in ethnic minorities). While information and knowledge are not guarantors of good health care decisions and adherence to recommended health behaviors, there is ample evidence that they contribute to them. Currently, substantial barriers prevent major segments of the population from seeking and/or using online health information. This paper provides an overview of the innovative Digital Divide Pilot Projects (DDPP) funded by the National Cancer Institute (NCI) to test new strategies for disseminating relevant health information to underserved and at-risk audiences, identifying strategies that libraries can adopt to provide digital health information to vulnerable populations.

## THE DIGITAL DIVIDE PILOT PROJECTS

In 2001, the NCI awarded close to \$1 million to help develop four innovative demonstration research programs to increase understanding about and examine new strategies for narrowing the digital divide that limits access to and use of relevant cancer information among many underserved populations [8]. The awards were an effort of NCI's Cancer Information Service (CIS) to work collaboratively with regional cancer control groups and organizations to test new strategies designed to enhance cancer communications in underserved communities. The CIS provides the US public with answers to questions they might have about cancer. It operates a national toll-free telephone network (1.800.4.CANCER), as well as an informative set of Internet-based Web pages and specialized cancer information and treatment search engines available through [www.cancer.gov](http://www.cancer.gov). By working with the Digital Divide Pilot Projects, CIS hoped to learn how to improve its outreach to diverse and underserved audiences of people who need relevant health information and support.

The NCI is a federal agency, part of the US Department of Health and Human Services (DHHS). It is the largest of more than twenty major research institutes in the National Institutes of Health (NIH). NIH's mission is to improve the health of the US public by increasing understanding of the processes underlying human health and by developing new and relevant knowledge about prevention, detection, diagnosis, and treatment of disease. A major NCI objective, in partic-

ular, is to significantly reduce the national burden caused by cancers by generating new knowledge about cancer prevention and control. To achieve these goals, NCI has developed an ambitious program of cancer research.

NCI is authorized by the National Cancer Act of 1971 not only to generate new scientific knowledge about cancer prevention, detection, and treatment, but also to communicate relevant new knowledge about cancer to health care consumers, providers, researchers, policymakers, and the public in general. In this regard, NCI has made a large and ambitious commitment to cancer communications research and outreach. In fact, NCI identified cancer communications as one of its priority areas for investment, an area of extraordinary opportunity [9]. The research and development projects described below are part of this extraordinary opportunity in cancer communications. The goal was to learn how to communicate effectively through new communication technologies with several hard-to-reach groups of people in the United States who are most vulnerable to the lethal effects of cancer. These research projects, called the Digital Divide Pilot Projects (DDPP) and carried out from 2001 to 2003, developed and tested new strategies for providing different poor and underserved groups of people with access to the latest and most accurate information about cancer prevention, control, and treatment [10].

Four innovative DDPP demonstration research projects were conducted in collaboration with CIS to identify effective new strategies for providing access to relevant cancer information to underserved populations: the Computerized Health Education and Support System (CHESS) Project, the Harlem Project, the Low-Literacy User Cancer Information Interface (LUCI) Project, and the Head Start Project.

### The Computerized Health Education and Support System (CHESS) Project

A University of Wisconsin-based research group, in collaboration with two CIS regional offices, one in Wisconsin and the other in Detroit, developed a multiyear demonstration research project to test the feasibility of working with the CIS network to disseminate an integrated online cancer communication system, CHESS, to underserved women recently diagnosed with breast cancer [11]. The CHESS information system is a unique computer-based support program that provides users with multiple information options (cancer information, reference materials, support groups, journaling, and so on). This project is a pilot test of a new information dissemination strategy to provide underserved cancer patients with access to an Internet-based version of the CHESS system with high-quality breast cancer information and support. Results from this study will test the broad dissemination of the CHESS system via the Internet. If it is successful, NCI and other organizations that provide cancer information services will be better able to develop innovative information dissemination strategies to reduce the digital divide among those facing cancer.

CHES could serve as a model for nationwide dissemination of Internet-based cancer information and support to the underserved.

Past studies found CHES to have positive effects, with high levels of utilization by test group members [12]. However, until now, the CHES system software has been installed on the computers used by respondents. This new study uses Internet delivery of CHES to a widely dispersed population of users to see if the system could have broader applications and dissemination potential with geographically distant audiences of potential users. A unique feature of this DDPP study is the comparison of adoption and use of the CHES system via Internet delivery by low-income women in rural Wisconsin and urban Detroit (the Wisconsin women recruited for this study are white and the Detroit-based women in the study are African American, providing an interesting comparison of system usage across race). Outcome measures showed that the system had positive effects on user satisfaction, well-being, support, and adjustment to living with cancer. System adoption, use, and satisfaction were consistently strong across the Wisconsin and Detroit populations, suggesting that the system works well for women from different racial and geographic backgrounds.

### **The Harlem Project**

The New York regional CIS office, in collaboration with researchers at the Memorial Sloan-Kettering Cancer Research Center in New York City, conducted an innovative community partnership intervention program designed to teach both consumers and providers of health care in Harlem how to access relevant cancer information on the Internet [13]. They conducted workshops teaching strategies for accessing health information online that were presented to target populations of lower-income minority groups (primarily African American and Hispanic) members at a network of community organizations that served as both technology access sites and training centers. The research team also developed culturally sensitive dedicated Websites for both health care providers and consumers to enhance the relevance and appropriateness of health information delivery.

A unique feature of this study was the use of established community organizations—including nonprofit community support organizations, local government agencies, and corporations—as delivery sites for information dissemination. These organizations provided easily accessible points of access for technology training and information searching. Results from this study demonstrate increased access to and use of relevant health information among target groups. This demonstration project shows how macrosocial community interventions—which coordinate the efforts of a number of community, government, and commercial organizations—can be used to help overcome the digital divide by ensuring that medically underserved populations have access to the same information and array of online tools as the rest of the population. This project

also provides an opportunity to develop and test new tools for bridging the digital divide. These tools, such as the CancerInfoNet.org Website developed in this project, are currently being made broadly available in this community.

### **The Low-Literacy User Cancer Information Interface (LUCI) Project**

Researchers at the Louisiana State University Medical School, in collaboration with the mid-South regional CIS office, developed an innovative multidimensional strategy to overcome the digital divide for low-literacy senior citizens in Louisiana [14]. Working through senior centers, this project uses a train-the-trainer program, a computer education program, installation of computer and Internet resources in state-operated senior centers, and an innovative, narrative-based, computerized multimedia information translation application (interface) for improving the dissemination of cancer information. The implementation of this LUCI interface uses multimedia technologies to overcome literacy-based barriers to computer use and the acquisition of cancer information. To engage seniors who are unfamiliar with computer and Internet usage, LUCI presents information in a multimedia narrative format, similar to a televised soap opera, that does not rely on reading or computer literacy.

Results indicate that the LUCI application is popular with the senior citizens and is easy for them to use. However, outcome measures have failed to demonstrate significant increases in health promotion knowledge and activity among the seniors. It may be that implementing the LUCI intervention over a number of years, rather than for a few months, would help the senior center incorporate the program more effectively in the organization. This project illustrates innovative strategies for reaching low-literacy audiences in senior centers and clinics that have the potential for broad application yet need refinements for more effective long-term institutionalization. The challenge is to find the best applications of this communication strategy and the most promising sites for program delivery.

### **The Head Start Project**

To provide low-income families with access to health information, the New England regional CIS office, in collaboration with researchers from Yale University, developed an important community intervention project that established community technology centers at two Head Start early childhood education program sites in New Haven, Connecticut [15]. In this innovative project, Head Start staff members were trained as technology coaches to deliver computer-training courses to parents and other community members, who earned free, refurbished, Internet-ready computers to take home by completing the training program. The unique focus in this project on the family as a unit of analysis, based on the Head Start program model, provided a rich multigenerational approach to development of computer skills and use.



This project, like the Harlem Project, provides a thought-provoking model for using established community resources to educate underserved populations and bridge the digital divide in access to health information. Results suggest strong acceptance of the program in the Head Start system, as well as positive influences on computer skills, health information access, and information utilization. There is great potential to develop similar technology centers in other Head Start programs, as well as in other community organizations, to help bridge the digital divide and provide underserved families with both access to and the skills to utilize relevant health information.

## IMPLICATIONS FOR LIBRARY OUTREACH

Each of these four Digital Divide Pilot Projects suggests important lessons for effective dissemination of relevant health information to underserved audiences.

### The CHES Project

The CHES project documented the use of an Internet-based integrated health information system to reach underserved urban and rural breast cancer patients in a cost-effective manner. The Internet-based delivery system suggests that similar online health information programs can have broad reach into different communities. Cost analyses documented that the costs of delivering CHES via the Internet were relatively modest (about \$200 per subject), compared with the cost of providing computers already loaded with the CHES program, as had been done in the earlier stage of the CHES project. This finding is important for health information dissemination programs for estimating potential costs for service delivery.

The Internet was found to be a very effective way of delivering information, training users, and gathering relevant information about information use and support needs. The CHES project benefited from development of innovative collaborations with public agencies, such as Medicaid, making it easy to reach and serve a large proportion of the low-income population. Similar collaborations with hospitals, public health agencies, and other programs aimed at low-income patients (for example, Wisconsin Well Women) were effective as recruitment vehicles, while other sources such as radio and television features had more impact on densely populated areas, such as Detroit, than in rural areas. The researchers are now engaged in studies to help identify what aspects of CHES make the difference in people's lives to determine the most cost-effective configuration of services. They are continuing to work with CIS to identify opportunities to take this initiative to the next level, with the goal of making CHES-like services part of the resources available nationwide through CIS. Much of what was learned in this project can be applied to library outreach, too, as libraries can serve as a focal point for the delivery of online health information services to consumers who do not have their own computers.

### The Harlem Project

In the Harlem Project, efforts have been made to make the CancerInfoNet.org Web tool broadly available. Certain features that made access cumbersome, such as the login requirement and the surveys, have recently been eliminated. A major promotion plan for the Website is under way, including placement on various email discussion lists and Websites of health agencies and academic institutions. Attempts are also being made to reach cancer patients and their families at the time of diagnosis, when they are most likely to need relevant health information. Sharing the model, the Website, and the training manuals with other NCI grantees, community-based organizations, and professional oncology organizations that want to implement a cancer education curriculum is also a priority. The partners in the interorganizational network established in this project continue to support the digital divide information dissemination goals and serve as important information intermediaries and technology centers for providing computer access for vulnerable members of the Harlem community. A lesson from the Harlem Project for libraries is to establish interorganizational networks in communities that can connect libraries to other important public and private organizations, so that they can collaborate on community-wide health information dissemination projects.

### The LUCI Project

Much of the LUCI digital divide project intervention remains in place at the participating senior centers to promote early detection of breast and cervical cancer and to offer the ongoing opportunity for improving computer and health literacy among the at-risk senior population. Several of the senior centers, as a direct result of the project, purchased and installed additional computers with Internet access. The Louisiana State University Medical School researchers are continuing to work toward expanding the content and functionality of LUCI for multiple kinds of cancer and extending its evaluation beyond senior centers to clinic-based settings in state public hospitals caring for the underinsured and the uninsured. Many questions remain about the acceptance and use of the intervention by low-literacy audiences when presented as part of primary or specialty care health encounters. The researchers are very interested in studying LUCI's direct effect on health literacy and health behavior when used for cancer prevention and early detection or for postdiagnosis cancer education. Moving the project into the state public hospital setting enhances the potential for carefully evaluating these outcomes, because controlled studies following LUCI's effect on patient health behaviors, such as the rates of cancer screening, can be accomplished more reliably. The researchers are also working toward further reducing dependence on computer and reading literacy for delivering cancer information by experimenting with the introduction of on-screen animated human hosts of multiple ethnicities that orally deliver cancer information and assist

the user in interacting with the computer. A major lesson from the LUCI project is the thought-provoking nature of narrative approaches to disseminating health information to low-literacy audiences, and an implication from this project for libraries is to incorporate more edutainment-focused interactive media programs for health education in public library settings. This suggests the importance of investing in new computer equipment and software to better serve the information needs of vulnerable audiences.

### The Head Start Project

In the Head Start Project conducted in New Haven, Connecticut, the community technology centers established in 2001 are still operational today. Additional computer training workshops were organized by Head Start staff even after NCI funding ended. Sustainability over the long term remains a challenge, however. Head Start is working with a local community-based organization, Computers for Families, to raise further funds to support the technology centers. From all reports, the computers delivered to families at the conclusion of training are, for the most part, still in use. Families with computers, many of whom live in public housing developments, report that they have become the hub of computer activity in their apartment complexes and neighborhoods. Part of the appeal of the project was the familiarity and credibility of Head Start with the target audience. Libraries can also establish partnerships with credible and familiar community organizations to deliver health education programs and services. Another important lesson from this project was the focus on the family in health information dissemination; libraries, too, could develop innovative family-based health education programs.

### CONCLUSIONS

Libraries can facilitate online access to health information among vulnerable and underserved populations [16]. Library education programs can help consumers recognize the need for health information by identifying problems associated with lack of relevant information for guiding good health decisions and achieving desired health outcomes. Libraries, by building on the information exchange relationship that they already have with many consumers, can help promote changes in health information-seeking intentions and practices [17]. Libraries can help institutionalize adoption of online health information by establishing viable programs for dissemination that evolve into sustainable, long-term, health-promoting relationships with consumers.

Each of the four digital divide pilot projects supported by NCI developed innovative community strategies for providing underserved groups of people with access to relevant computer-based information about cancer. There is great opportunity to expand and sustain these digital divide interventions to provide other underserved populations with relevant health information. There may be some opportunities to combine

aspects of these projects for application in different contexts, such as in libraries. Lessons learned from these projects can be fruitfully applied in many other settings to narrow the digital divide and reduce health disparities. These projects attempt to increase understanding of why barriers to information and knowledge exist, and the data gleaned from these pilot projects can be used to design programs that can lead to better health care decisions and adoption of recommended health behaviors. These pilot projects will serve as models for larger-scale efforts. Similar efforts to narrow health disparities by bridging the digital divide can help empower underserved health care consumers to make informed health care decisions, seek the best possible health care, and enhance their quality of life. The results of these Digital Divide Pilot Projects should be interpreted and applied to develop new programs and policies that provide relevant health information to all segments of society.

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