# Expanding the
# REACH AND IMPACT of Consumer E-HEALTH TOOLS

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Office of Disease Prevention and Health Promotion

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# PREFACE: A VISION OF E-HEALTH BENEFITS FOR ALL

This report summarizes a study undertaken by the Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services, on the potential utility and value of consumer e-health tools for populations that experience health disparities. As the report notes, the rapidly expanding use of information and communication technologies, particularly the Internet, by multiple sectors of the population indicates that there is an opportunity to use these same technologies to improve population health. Many conditions, however, must be met before opportunity becomes reality. The report examines and describes the most significant requirements as well as provides a vision to help guide the development of an inclusive environment of e-health benefits for all.

The following fictional profiles of Juan Lopez and Barbara Jones personify two emerging groups of e-health consumers. Barbara is a well-educated, middle-class female, age 47, who is actively involved in managing her health and that of her family and knows a lot about health and health resources. She owns multiple computers (desktop and mobile), has high-speed Internet connections, and is technologically savvy. Juan, age 34, is an equally important part of the e-health vision articulated in this report and of the reality described here, even though he has none of these characteristics, has limited health literacy, and is new to e-health.

Juan and Barbara have more in common than might be apparent at first glance. Both have access to e-health tools that provide new and vital information about their health. Both are concerned enough about their health and that of their families to want to be involved in managing it and making informed decisions. For different reasons, both know they need to rely on themselves, not just healthcare professionals, for continuous and complete care, and both are learning to use several interrelated e-health tools for these purposes.

Juan, Barbara, and their families are introduced here to illustrate the breadth and diversity of the e-health landscape depicted in this report. In addition to the user-centered approach proposed for all e-health tools, Juan's story illustrates the need for outreach, community technology access, and training to create the conditions for meaningful access for all population segments. With these additional investments, e-health resources can serve his needs and interests as well as they do Barbara's and can promote equity in healthcare services and information access.

**Juan Lopez** and his family are migrant farmworkers who follow the crop cycles through the western United States, arriving by late summer in Sonoma Valley, California, for the grape crush. There they live in simple housing and receive health care from the St. Joseph's Healthcare Services Mobile Medical Units and other services from Vineyard Worker Services (VWS). Since 2002, Juan and his wife, Maria, have been able to maintain electronic health records for themselves and their children through the MiVIA program *(www.mivia.org)*. Their password-protected personal health records contain their providers' records on medical visits, test results, and other clinical data. In addition, they can keep records on their son Lupe's blood sugar and other health matters and communicate with the doctor through secure e-mail.

At the first visit to the VWS clinic, the outreach worker, Ricardo, helped enroll the Lopez children in the Healthy Families public insurance program. Now that they have access to primary care, the family is able to avoid the emergency department visits that used to punctuate their lives. When Lupe was diagnosed with juvenile diabetes, Ricardo downloaded self-care information in Spanish from MedlinePlus, showing Maria how to search for information through her MiVIA Internet connection. He also printed Spanish-language information on the family's prescriptions, making them much more comfortable in taking the confusing medications. Juan likes the fact that he can keep notes on the shoulder pain he's experienced for years so he can describe it to his doctor.

One of the most valuable MiVIA resources for the family is the portable personal emergency card, providing electronic access to information on health conditions, medications, allergies, immunizations, and enrollment. Wherever they go, these cards enable family members to share information with medical providers and to maintain a continuity of care record. Juan's shoulder problems are less acute, Lupe now receives consistent care for his diabetes, and the children did not require re-immunization because their schools and doctors have their immunization records. Juan and Maria can access their personal health record home pages and link to the Internet on public computers set up by the California Endowment in several locations in the valley.

When they first heard about VWS, Maria and Juan were both leery about trusting a public clinic and even more so about keeping their records electronically on MiVIA. However, the trained *promotora* (community health worker) they met at the laundromat assured them that the program exists only to help them and that their privacy would be protected. Within a few months, Maria was so enthusiastic about the program and her new sense of empowerment that she agreed to join the VWS Farmworker Advisory Group.

**Barbara Jones** runs her own business, a travel agency, and uses technology for her home business and to manage her own health as well as that of her family. They own two desktop computers and multiple mobile computing devices, all with high-speed Internet connections. Her husband Doug has asthma, and their son Jonathan has a learning disability.

As do most consumers, Barbara uses a search engine to find information on the Internet. After spending a lot of hours surfing and sorting through Web sites—some with reliable information, others pitching quick fixes and unproven products—Barbara found *www.healthfinder.gov*, the Federal Government's gateway Web site for consumer health information. Barbara returns regularly to the site, most recently to browse the section on perimenopause and take a quick quiz. She downloaded the information into her personal library in her online personal health record. She also read the privacy policy of *www.healthfinder.gov* and was reassured that the site does not collect or store information about its users.

Barbara has a membership with a commercial Web site where she has created personal health records for herself and her family. Before she selected this site, she spent many hours analyzing different services and companies. Barbara settled on a site that clearly explained its services, pricing, and guarantees, including privacy protections. She uses an ID and password to access the records.

On a typical day, Barbara receives system reminders in her e-mail to log in and record any updates on her husband's and son's conditions. Barbara plans to review Jonathan's new medications that the doctor prescribed yesterday and the calendar with the automated reminder system for Jonathan's next visit. She also will double-check the time of an appointment she has scheduled with a cardiologist. Barbara completed an online assessment that suggested she might be at risk for heart disease and should consult a physician.

Barbara's women friends use many of the same online health resources she does. Several have tried a popular online weight loss program, and one has used an online program to quit smoking. They all like the convenience and privacy. She and her friends often share tips that they glean from various chat rooms. In her town, few of the office practices have electronic health records, let alone personal health records and other tools for their patients. Barbara did receive a mailing from her health plan telling her that they would add new features to their Web site; however, at present, the site contains only general benefits information, provider directories, and health information that she already finds on her own. She is comfortable being ahead of the curve and feels she is getting better care for her family by using online information and services.

## A VISION FOR CONSUMER E-HEALTH FOR A DIVERSE POPULATION

The illustrations above suggest that a broad and inclusive vision of consumer e-health is needed to ensure equitable access and appropriate content for all. This report proposes the following vision to help shape emerging policies, research, and practices. The vision is only the first step needed to galvanize attention, motivate action, and stimulate partnerships to create a sustainable consumer e-health arena.

- Consumers with diverse perspectives, circumstances, capacities, and experiences are included in the design of, and have meaningful access to, evidence-based e-health tools with strong privacy and security protections.
- Diverse consumers have the skills and support to evaluate, choose, and use e-health tools to derive benefits for themselves and those they care for.
- Healthcare organizations and practitioners use the full range of e-health tools to engage and support diverse consumers in their own health management as a routine element of care.
- Local, state, and national policies and programs support the sustainable development and dissemination of evidence-based consumer e-health tools to diverse individuals and communities, including those served by safety-net providers.
- Alliances and partnerships facilitate sustained consumer access to and use of e-health tools, consistent with the value propositions and perspectives of each participating stakeholder.
- Appropriate funding and incentives exist in public policy and the market to enable sustainable business models for tools with demonstrated effectiveness.

## A CAVEAT ABOUT PRIVACY AND USABILITY

Since the beginning of this study, the interrelated issues of trust, privacy, and consumer control have moved to center stage in public policy discussions. These issues are clearly of critical importance to consumers, as shown in survey and focus group research by the Connecting for Health consortium and others. The security measures being developed, combined with education and transparency about the uses of personal information, are essential to assuring consumers that everything possible is being done to protect their personal information.

The vision stated above specifically includes the requirement of strong privacy and security protections, but the report does not include in-depth discussions of privacy, confidentiality, and security issues that are currently being addressed in other venues (for example, see the public record of the Subcommittee on Privacy and Confidentiality, National Committee on Vital and Health Statistics at *www.ncvhs.hhs.gov*). What the present study does contribute is the recognition that population diversity plays a role in understanding consumer attitudes and needs in this area, as in others. Individuals, as well as population groups, view the tradeoffs between the benefits and risks of electronic health information differently, suggesting the need for some choice in functionality and types of e-tools, as well as targeted education, communication, and support. Chapter 2 discusses this idea as part of the constellation of factors that require further consumer research and analysis.

At the same time that privacy and consumer control should be taken seriously as factors inhibiting the spread of consumer e-health tools, equal attention should be given to factors of usability. It is possible to envision a scenario in which consumers are satisfied with the control they have over their personal information, yet are frustrated by e-health tools that do not meet their usability requirements. For example, envision a personal health record that has the most advanced security features and sound privacy policies and guarantees consumers control over access to the record. This same personal health record, however, may also be designed in such a way that it is difficult to enter or transfer information from one application to another, involves too many steps to set up the record or conduct a transaction, displays confusing or overwhelming amounts of information on each screen, and is lacking in adequate technical support.

Consumers should not have to choose security, control, *or* usability. As the vignettes illustrate, consumers seek security, control, *and* usability. The key message of this report is that, without a greater focus on user requirements and accessibility issues, consumer e-health tools may fall far short of their potential for personal health management or population health improvement.

# EXECUTIVE SUMMARY

## CHAPTER 1. INTRODUCTION

The economic pressures of ever-increasing healthcare costs and suboptimal health outcomes are driving the search for new approaches to health management. Policymakers and even the President now speak of the National Health Information Network and interoperable electronic health records as necessary elements of health care for the entire population. Based on multiple studies and reports on the need for patient-centered health care, public policy is attaching growing importance to the role of consumers in managing their own health, in partnership with healthcare providers.

Consumer-oriented e-health resources are meant to help consumers manage the heavy demands of health management. Indeed, it may be difficult for consumers to meet some of the demands without e-health tools. "e-Health" is a broad term for the heterogeneous and evolving digital resources and practices that support health and health care. e-Health resources enable consumers, patients, and informal caregivers to gather information, make healthcare decisions, communicate with healthcare providers, manage chronic disease, and engage in other health-related activities. Most, although not all, of these resources are available through the Internet. e-Health tools offer consumers a broad range of integrated, interactive functions including those listed below. Most tools support several of these functions, generally structured around a primary purpose such as disease management.

- **Health information—**either a spectrum of searchable information or more narrowly defined content
- **Behavior change/prevention—**support for a specific behavior change such as smoking cessation
- **Health self-management—**tools for achieving and maintaining healthy behavior in lifestyle areas such as diet and exercise
- **Online communities—**Internet-based communities for interaction among consumers, patients, or informal caregivers about shared health concerns
- **Decision support—**structured support for making treatment decisions, choosing and evaluating insurance programs or healthcare providers, or managing healthcare benefits
- **Disease management—**monitoring, recordkeeping, and communication devices for managing a chronic disease, usually in conjunction with healthcare providers
- **Healthcare tools—**means of maintaining or accessing health records and interacting with healthcare providers. This category includes personal health records.

These tools show great promise for enhancing the health of users; at present, however, they fall short of offering population-wide benefits. The national commitment to eliminating health disparities and improving health literacy intensifies the need for a thorough understanding of consumers and their requirements for e-health tools. Some of the most important benefits of e-health tools—if properly designed and disseminated—could potentially extend to underserved Americans, who often bear the greatest health burdens with the least support. Even as more consumers become comfortable with the Internet as a health resource, questions remain about the value of e-health tools for many segments of the nation's diverse population. This study found that there do not appear to be intrinsic deficiencies in technology or insurmountable access obstacles; rather, the issue is that not enough tools have yet been designed and disseminated with an eye to the diverse experiences, requirements, and capacities of end users.

This study treats diversity as a key concept in analyzing the e-health phenomenon. Its purpose is to identify and analyze the critical factors influencing the reach and impact of consumer e-health tools for a diverse population. It addresses questions about what motivates and engages different users, reviews the research literature, examines e-health dissemination models, and identifies gaps and opportunities in policy, tool development, research, and dissemination. The following vision provides the guiding principles and the yardstick against which current conditions are assessed:

- Consumers with diverse perspectives, circumstances, capacities, and experiences are included in the design of, and have meaningful access to, evidence-based e-health tools with strong privacy and security protections.
- Diverse consumers have the skills and support to evaluate, choose, and use e-health tools to derive benefits for themselves and those they care for.
- Healthcare organizations and practitioners use the full range of e-health tools to engage and support diverse consumers in their own health management as a routine element of care.
- Local, state, and national policies and programs support the sustainable development and dissemination of evidence-based consumer e-health tools to diverse individuals and communities, including those served by safety net providers.
- Alliances and partnerships facilitate sustained consumer access to and use of e-health tools, consistent with the value propositions and perspectives of each participating stakeholder.
- Appropriate funding and incentives exist in public policy and the market to enable sustainable business models for tools with demonstrated effectiveness.

This report stresses that e-health practices have the potential to be part of the solution to health disparities and other health policy challenges if appropriate and useful e-health resources are made available to a larger proportion of the U.S. population than is now the case. So far, market forces and fragmented public-sector efforts have failed to harness technological innovation to improve population health. Some observers worry that an uneven distribution of high-quality e-health tools or consumers' varying ability to use such tools could worsen health disparities. The report proposes that extending the benefits of these technologies to diverse users requires public leadership, robust public-private partnerships, and consumer-centric research, analysis, and strategies. The entire effort must be connected both to the disease prevention and health promotion objectives for the nation in *Healthy People 2010* and to the goals for the emerging National Health Information Network.

This study explored the following questions:

- What is known about population diversity that can inform the creation of appropriate e-health tools and enhance understanding of their uses?
- How is the research base for consumer-centric e-health tools evolving?
- What factors in public policy and the marketplace are influencing the development and dissemination of e-health tools?
- What gaps are not likely to be filled by market-driven solutions and should be addressed by public policy and public-private collaborations?
- What approaches exist and might be expanded to connect diverse groups of consumers with e-health tools?

The study team took a critical approach, searching below the promising surface of e-health, to examine gaps between promise and reality. The study draws on many earlier studies, reports, and articles. In particular, it builds on the work of the Federal Office of Disease Prevention and Health Promotion (ODPHP) Science Panel on Interactive Communication and Health, which authored a report assessing the interactive health communication field at that stage (U.S. Department of Health and Human Services, 1999). The present study identified or confirmed several encouraging trends in the consumer e-health arena and identified several issues raised in earlier reports that still have not been adequately addressed. Literature reviews of published and unpublished studies, an environmental scan, interviews, and meetings with e-health researchers and developers, public health officials, community technology professionals, and other experts led to the following five findings:

**Finding 1.** Achieving broad public acceptance of personal health management and e-health tools will require greater attention to the intended users' diverse perspectives, circumstances, and experiences regarding health information and digital technologies, as well as their differing capacities for health management. (See Chapter 2.)

**Finding 2.** A large body of evidence suggests the effectiveness and utility of many consumer e-health tools. The evidence is uneven across categories of tools and user groups, however. Often, the tools are developed as research projects and not easily available in the marketplace; conversely, many tools in the marketplace do not have an explicit evidence base. Consumers may not be able to access many evaluated e-health tools that would be beneficial to their health, particularly given the increasing demands related to personal health management. (See Chapters 3 and 4.)

**Finding 3.** In addition to the lack of alignment between evidence-based and popular tools, other significant gaps include the shortage of viable and sustainable business models, the need to protect health information privacy and nurture public trust, and the need for ongoing quality assurance. (See Chapter 4.)

**Finding 4.** The e-health arena comprises many stakeholders besides consumer end users, including healthcare organizations, purchasers, public health entities, employers, community-based organizations, and others. Many are already engaged in partnerships around funding, dissemination, research, development, and advocacy. The personal health record arena has generated early collaborations around a tool that may prove useful to diverse user groups and provide a platform for multiple e-health functions. Both coordination and Federal leadership are needed to achieve the vision proposed in this report, possibly modeled on these activities related to personal health records. (See Chapters 4 and 5.)

**Finding 5.** Strategies for reaching diverse audiences have been developed and have proven effective in communities outside the digital and economic mainstream. These strategies could provide models for new efforts to reach diverse, often underserved audiences, complementing more standard market approaches and widening the reach and impact of e-health tools. In addition, future e-health dissemination efforts may be able to leverage the networks they have already created. (See Chapter 5.)

## CHAPTER 2. MAPPING DIVERSITY TO UNDERSTAND USERS' REQUIREMENTS FOR E-HEALTH TOOLS

As noted, the vision for consumer e-health tools that informs this report emphasizes the importance of diversity and user-centric approaches. Diversity has many dimensions, including but not limited to cultural, economic, educational, and experiential factors. This study confirmed earlier findings that little consumer research is available, particularly at the subpopulation level, to inform projections of who will use e-health tools in general, who will use specific tools, and how the use of these tools will affect their perceived and objective health status.

The idea of health literacy is emerging as a powerful construct for identifying the environmental and human factors that influence the ways in which people interact with health information and the healthcare system. Health literacy is defined as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. The construct unites the issues of individual and group capacity, access, and understanding. Researchers and practitioners working on issues of technology access have developed the closely related construct of "meaningful access" to convey a similar idea that equipment and Internet connections as well as skill development, ongoing technical support, and appropriate content are all necessary to close society's "digital divide." These constructs are useful in assessing what is needed to make e-health tools useful to diverse audiences. Digital disparities should be a matter of great concern for public health and medicine because many of the same segments that lack adequate Internet access also have the highest risks of developing, or already have high rates of, chronic diseases. If public and private policies put greater responsibility for personal health management on any of these population groups, then policymakers must give serious consideration to the types of support—digital and nondigital—that consumers will need to carry out their responsibilities.

Significantly, there are indicators that Internet access is growing in every segment of the population and that many of these segments are ready to think about new uses of the Internet and other digital technologies for health. Much more information is needed, however, about factors related to users' motivations, engagement, and understanding regarding e-health tools and the relevance of these factors in supporting greater use. A scan of the current field of e-health tools indicates that developers are beginning to address issues of diversity. However, most strategies and approaches do not go beyond traditional public health targeting based on demographic characteristics. Although important, characteristics such as race and ethnicity are mediated by many other factors, including age, life experience, culture, health and caregiver status, education, and income.

This study brings together what is known about factors to be considered when designing and disseminating e-health tools for diverse populations. These factors include language; cultural factors; socioeconomic position; disabilities; age, developmental, and role issues; interest in health information; and attitudes about privacy. If the vision of *e-health benefits for all* is to be realized, the critical factors for user-centric design will require additional research and integration into tool design, development, and dissemination.

## CHAPTER 3. ASSESSING THE EVIDENCE FOR E-HEALTH TOOLS FOR DIVERSE USERS

Several reviews of the research literature have noted both the promise of e-health tools and the multiple factors that limit their effectiveness. The literature review conducted for this report focuses on which e-health tools work well for diverse users and on where additional and different research is needed to address disparities and improve population health. This chapter uses the following attributes to organize the findings from the research literature and assess their implications for serving diverse populations:

- Access
- Availability
- Appropriateness
- Acceptability
- Applicability of content

The review found that meaningful comparisons among tools and across research studies are difficult if not impossible due to the variety in tool design, samples used, topics covered, and origins of the tool (i.e., research or market-based). Although the literature review (and the environmental scan described in Chapters 2 and 4 and Appendix 1) identified a large number of tools, there are no standard, accepted definitions for the purposes or functions of consumer-oriented tools. Most of the e-health tools in the studies reviewed are multicomponent interventions designed to affect many aspects of personal health self-management, including prevention, behavior change, decisionmaking, and chronic disease management. Each tool contains health information specific to its intended purpose. Tools designed for a similar purpose do not always contain the same components.

Although e-health tools have been developed for a wide variety of topics and purposes, some appear to be better represented in the research literature than others. Areas with the largest numbers of tools are nutrition education, weight management, tobacco cessation, cancer prevention and management, and diabetes prevention and management. Although most of the tools studied were designed for adults, some target children and adolescents. Some tools, such as those for behavior change, are grounded in a theoretical framework. Others, such as healthcare tools, are emerging in response to market and policy demands and do not yet have enough of a scientific basis to suggest that they will have their intended effect. The study samples have a strong bias toward persons who already use computers and have Internet access.

The key findings, organized according to the attributes listed above, are described below.

**Access.** Large numbers of e-health tools have been developed, but it is not known how many people know about these tools, how many are using these tools outside of research studies and closed healthcare systems, and how many may be willing to try them. Few, if any, data exist on the distribution of e-health tools across the population or within subgroups. The ability of interested users to locate and access these tools, particularly those with credible research, is also unknown.

**Availability.** Many of the studies utilized convenience samples or required computer ownership. This approach has led to a disproportionate amount of information on Caucasian women with higher education levels. The lack of diversity in the research samples and limited evidence indicating differential effects based on demographics suggest major gaps in knowledge. These gaps include how to address issues of access as well as the acceptability and appropriateness of personal e-health tools for large segments of the population.

**Appropriateness.** Some tools have been developed that target special populations, and some of these were developed with input from the target audience. These studies show that with careful attention to cultural, literacy, and technological needs, successful tools can be developed for and used by diverse groups. User-centered design and usability research (discussed in Chapter 2), along with participatory research methods, can be used to bridge the gap between what designers and researchers envision and what the ultimate end users find engaging and helpful.

**Acceptability.** People like e-health tools and generally find them easy to use. Although usage seemed to decline over time, the declines were not as steep as those found in the control conditions. It is not known how this decline compares to other intervention formats, such as in-person educational or therapeutic programs.

**Applicability.** Many studies found positive changes in knowledge and intention after just one interaction using e-health tools. Findings on actual behavior change and health outcomes have been less clear. However, many of these studies may not have provided interventions with enough frequency or intensity to bring about desired changes in these areas, or they may not have used appropriate control groups. Many studies relied on self-reported data to document change.

## CHAPTER 4. STRATEGIC FACTORS IN REALIZING THE POTENTIAL OF E-HEALTH

Consumer e-health is part of the broad cultural shift toward using technology and the Internet as a normal part of everyday life. The dynamic e-health arena is evolving rapidly in response to multiple cultural and technological trends, market and health system forces, and policy initiatives. The growing diversity of the e-health market is an important sign of its vitality; the momentum toward e-health now touches nearly every segment of society, albeit to different degrees. Many stakeholder groups besides consumers, patients, and caregivers are involved with consumer e-health, bringing a broad range of interests and motivations to this arena. Healthcare organizations and health plans are major drivers. Table 4 on page 69 summarizes stakeholder perspectives on the benefits of consumer e-health.

Today's e-health market also has many limitations, suggesting the need for more concerted action by public and private stakeholders to stabilize and strengthen this arena in the public interest. In addition to those discussed in previous chapters, the limitations include a lack of coordinated approaches to e-health tool development, evaluation, and dissemination; a lack of sustainable business models for e-health tools; the need for stronger privacy protections to nurture public trust; and an ongoing need for quality assurance. Achieving the goal of getting appropriate evidence-based e-health tools into wide and sustained public use requires coordinated strategies in the following areas:

- Strengthening the links among e-health tool development, evaluation, and dissemination
- Building viability and sustainability for e-health tool developers and suppliers
- Protecting the privacy of personal health information
- Assuring the quality of tools and services available to consumers.

As the guardian of the public interest, the public sector has ultimate responsibility for ensuring these limitations are addressed. Government-coordinated strategies in these areas could support existing public programs and help advance a number of important public policy goals, including supporting consumers in taking more responsibility for their health and eliminating health disparities. Government cannot achieve these changes by itself, however. The stakeholders who share an interest in consumer e-health—including consumers, developers, and researchers as well as healthcare organizations, purchasers, employers, and public health programs—are all potential participants, in various combinations, in efforts to enable more Americans to enjoy the benefits of appropriate e-health tools. Current joint industry-Government activities to stimulate the development, dissemination, and adoption of electronic health records may provide a useful model of a concerted, large-scale effort of this kind.

## CHAPTER 5. PARTNERSHIPS FOR MEANINGFUL ACCESS

A variety of models have been developed—both in the healthcare and public health fields and in the wider arenas of community development and civic life—to build new constituencies for technology in the public interest. The final chapter of this report profiles organizations and projects in the public and nonprofit sectors that use creative strategies to reach diverse and underserved communities. These strategies include:

- Using the existing community infrastructure to provide training and open access in underserved communities
- Implementing a statewide strategy involving multiple partners
- Reaching out to target audiences
- Supporting research and development involving diverse audiences.

These projects share a number of important attributes:

- The projects illustrate comprehensive approaches to achieving meaningful access.
- They involve a large number of partners and stakeholders, as demonstrated particularly well in an example from California.
- The projects use participatory approaches that engage consumers not only as targets and recipients, but also as cocreators of content and services. They are created *for, by,* and *with* diverse communities.
- They offer sustained, continuous services at the community level. Library programs exemplify this attribute, although their longevity cannot be taken for granted.
- Finally, all these projects leverage significant resource commitments from a range of sponsors—including Federal agencies, industry, and foundations—and serve as important vehicles for their sponsors' missions and program objectives.

All these principles and attributes will be critical for future initiatives to widen the reach and impact of e-health tools.

## CONCLUSION

Today, more and more decisionmakers are interested in e-health tools as critical components of personal health management and healthcare reform strategies. Decisionmakers are seeking viable approaches to reduce healthcare costs, improve the quality of care, and increase consumers' ability to manage their own health. Conditions are favorable for a greater investment in consumer-oriented e-health tools. The technology marketplace is dynamic; the public is increasingly turning to information and communication technologies for a better life; healthcare organizations are adopting and offering health information technology; and Government policy is placing great emphasis on both health information technology and personal health management for consumers. Such activities are now part of everyday news.

Since this study began, the Federal Government has embarked on a major initiative to increase the use of health information technology by healthcare providers and consumers. The creation of the Office of the National Coordinator for Health Information Technology within the U.S. Department of Health and Human Services (HHS) provides a strategic opportunity for the Federal Government to exercise the kind of leadership called for in this report.

Improving population health and personalizing health care—key components of the vision underlying this study—are two of the four goals articulated in HHS' Framework for Strategic Action for health information technology. The vision and approaches proposed in the present study should be useful in realizing both the population and personal health goals.

The present study seeks to lay the foundation for a robust, population-wide, and consumer-centric e-health enterprise. It outlines a vision, identifies challenges and opportunities, and highlights strategies for using e-health tools to improve personal and population health. A central message is that no single tool or strategy will work for a national population with highly diverse interests, experiences, conditions, and capacities. This study found that, at present, the well-documented diversity in this country is not well matched by the diversity of strategies and responses in the e-health arena. This is the case for e-health tools themselves as well as the policies, funding, and program priorities that influence their development, evaluation, and dissemination.

Realizing the potential population health benefits of e-health tools requires not only a shift in thinking and strategies but also strong leadership to coordinate marketplace and policy momentum for maximum public benefit. Disparities in access to health information, health care, and technology make it highly unlikely that market forces and fragmented public-sector efforts alone will achieve desired public health goals. Consistent with other Government initiatives, public-sector engagement in partnerships that harness current consumer trends and align the multiple interests of stakeholders is crucial. The way forward for consumer e-health is to use these partnerships and interests to create and sustain a user-centered strategy that results in e-health tools being available on a much wider scale than is currently possible.

# CHAPTER 1. INTRODUCTION

The economic pressures of ever-increasing healthcare costs and suboptimal health outcomes are driving the search for new approaches to health management. Policymakers and the President now speak of the National Health Information Network and interoperable electronic health records as important and necessary instruments of health care for the entire population (Bush, 2004a; NCVHS, 2001; Thompson and Brailer, 2004). The President has also called for universal, affordable access to broadband technology by 2007 (Bush, 2004b).

Consumer-controlled electronic health records, or personal health records, are an element, likely a cornerstone, of evolving "personal health record systems" (NCVHS, 2005a). These emerging systems signify the growing momentum of the consumer e-health phenomenon, in which consumer engagement, decisionmaking, and tools come together to support and enhance health (Tang and Lansky, 2005).[1] The Internet, in particular, facilitates the spread of consumer e-health and has become a popular public channel for finding health and healthcare information and communicating with peers and health experts (Fox, 2005b).

The idea behind much of the current policy interest in e-health is what is commonly called "personal health management." This term is used by an increasing number of organizations, thought leaders, and policy documents to describe individuals' responsibility for their own health (Connecting for Health, 2004; IOM, 2001; NCVHS, 2001; Thompson and Brailer, 2004). Although many, if not most, consumers already do much of their own coordination to cope with a fragmented healthcare system, the underlying assumption of personal health management is that individuals both want and will have to take even more responsibility for and control of their own health and health care.

The concept of personal health management refers to individuals' orientation toward their health, information, and healthcare services as well as their capacity to engage in tasks that require ongoing attention. Personal health management implies that everyone has at least some capacity, no matter how limited, that can be applied to decisions and actions about health. For example, highly "activated," capable consumers would regularly seek out health information, maintain or cultivate a healthy lifestyle, participate in shared decisionmaking with providers, monitor health conditions, maintain personal health records, and compare healthcare cost and quality. Less

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[1] Numerous terms have been used to describe the intersection of information and communication technologies and health; "e-health" has become the preferred term. A recent review article confirmed e-health as "the use of emerging information and communication technology, especially the Internet, to improve or enable health and health care" (Pagliari, Sloan, Gregor, et al., 2005).

activated persons might perform these tasks less frequently, less systematically, or with less precision; or they might ask someone else to do it on their behalf.

This report focuses on the electronic tools that offer many consumers a broad range of integrated, interactive functions to enable personal health management. For those consumers who are least able to cope with the volume of health information, decisions, and care coordination, these tools—if designed and disseminated appropriately—could potentially ease the burden. The functions include the following:

- **Health information.** Virtually all e-health tools provide access to health information, either a spectrum of searchable information or more narrowly defined content. Providing information is the main or sole purpose of some tools.
- **Behavior change/prevention.** Some e-health tools are designed to support a specific behavior change, such as stopping smoking or binge drinking, starting regular exercise, or getting a mammogram. Most prevention-related tools are developed through research with defined target audiences under controlled conditions.
- **Health self-management.** Consumers use health self-management tools to achieve and maintain healthy behavior in various lifestyle areas such as diet and fitness. Some are marketed online directly to consumers; others are distributed by employers, health plans, and insurance companies.
- **Online communities.** Internet-based communities facilitate interaction around common health concerns among consumers, patients, or informal caregivers. Many online communities have multiple capabilities—not only providing social support, but also exchanging health information and facilitating decisionmaking. Many disease management tools and some with other functions offer users an online community option.
- **Decision support.** The tools in this category provide structured support to consumers. Some tools support treatment decisions, such as weighing the tradeoffs between different cancer treatments. "Demand management" tools help consumers choose and evaluate insurance programs or healthcare providers. Managing healthcare benefits is a related e-health tool function. Demand and benefits management tools are growing in prominence as a function of prevailing "consumer-driven" strategies, such as health savings accounts.
- **Disease management.** These tools provide monitoring, recordkeeping, and communication devices to help consumers manage a specific disease, such as diabetes or cancer, typically in close interaction with healthcare providers.
- **Healthcare tools.** These e-health tools facilitate interaction between patients and clinical professionals and healthcare organizations. Some tools may be free-standing, such as personal health records (PHRs) provided by a non-healthcare entity, or they may be available to patients or members, who have considerable control over their use.

> The most common forms of healthcare tools are PHRs, patient portals, and secure doctor-patient e-mail. PHRs and portals are a gateway to many other e-health functions and may become the way that most Americans are introduced to e-health tools.

Most e-health tools support several of the above functions, generally structured around a primary purpose such as disease management. The linking of functions makes it possible, for example, for Medicare enrollees who log on to the Beneficiary Portal not only to view their claims history but also to search the National Library of Medicine's MedlinePlus for information on a health condition or to use a search engine to find a commercial e-health product to help with smoking cessation. Migrant farmworkers who keep family health records online with the MiVIA program (see Preface) could also use that service to e-mail the doctor, download nutritional information, or participate in a Spanish-language online community. The discussion of the attributes, strengths, and limitations of e-health tools continues in Chapter 3 as part of the review of current research.

Now that many e-health tools are available in the marketplace and public policy is increasingly interested in promoting their use, key questions arise: How much demand is there for these tools? How appropriate are available tools for a diverse public? Who will serve those consumers who are uninsured or are part of the healthcare safety net if the market does not perceive sufficient financial opportunity?

The purpose of this report is to identify and analyze the critical factors influencing the reach and impact of consumer e-health tools for this country's diverse population, including those traditionally described as "underserved." The report follows the concept of diversity proposed by the Institute of Medicine (IOM): diversity is a sociocultural process that represents the collection of life experiences, attitudes, behaviors, perceptions, sociocultural conditions, and capacities associated with an identifiable group (IOM, 2002).

The report addresses questions about what motivates and engages different users, reviews the research literature, examines e-health dissemination models, and identifies gaps and opportunities in policy, tool development, research, and dissemination. The report is based on review and analysis of the scientific literature; published and unpublished studies and reports on health communication, consumer e-health, health information seeking, Internet access, and health information issues for minority groups; publicly available survey research; field reports; expert input, including one-on-one interviews, group conference calls, in-person meetings, and document review; environmental scans of publicly available consumer-oriented e-health tools; and interviews with e-health tool developers.

This study found that, even as more consumers become comfortable with the Internet as a health resource, questions remain about the utility of e-health tools for this country's diverse population. The report proposes that not enough tools are yet designed and disseminated with end users' experiences, requirements, and capacities in mind. It concludes that extending the impact and benefits of these technologies requires public leadership, robust public-private partnerships, and consumer-centric research, analysis, and strategies. The entire effort must be connected to the disease prevention and health promotion objectives for the nation that are articulated in *Healthy People 2010* (HHS, 2000), as well as to the Government's goals for the emerging National Health Information Network (Thompson and Brailer, 2004).

There is little doubt that all Americans need good resources to help them manage their health, along with the skills and support to use the resources effectively. Powerful forces and trends are converging in health care, employment-based insurance, and public policy to create challenging conditions for all users of the healthcare system. Healthcare costs are growing, and more and more costs are being shifted to consumers. Americans are more likely to live with multiple chronic diseases and less likely to have adequate health insurance. Meanwhile, healthcare providers increasingly expect patients to use Internet-based technologies, including PHRs, and to engage in sophisticated health management activities. Any one of these forces can be challenging for consumers; in combination, they can create financial, technological, and informational demands that for many could be overwhelming.

e-Health technologies are meant to help consumers confront these demands; indeed, it will be difficult to confront some of them *without* e-health tools. Some segments of the population, however, are not ready or able to perform the personal health management roles into which they are being cast. Especially vulnerable are those who are not yet persuaded of the value of e-health, often because they do not see it as relevant to their lives or they have serious concerns about the privacy of personal information; those who do not have meaningful access to technology solutions; those who do not yet have the capacities to use information or technology effectively; and those for whom available technology solutions are currently inappropriate. The concern of many Americans about the privacy of their personal health data imposes a serious barrier to adoption (California HealthCare Foundation, 2005).

Appropriate and effective tools are not yet available to many Americans, either because the tools have not yet been developed or because dissemination mechanisms are inadequate. Research indicates that, at present, the health information system—both print and digital—is inadequate to serve many Americans (IOM, 2002, 2004). Available health information is often needlessly jargon-filled, dense and complex, and in many cases not in the right language, style, or format for the intended beneficiaries of the information (HHS, 2003). The limited literacy skills of many segments of the population make it difficult for them to find and understand basic health information, engage in informed decisionmaking, and manage the consequences of their decisions (IOM, 2002, 2004; Shaller, 2005).

The reliability of health information available to the public has also been questioned; the quality of Internet-based health resources, as well as health information in the mass media, has been a major preoccupation of health professionals (Eysenbach, Powell, Kuss, et al., 2002; Seidman, Steinwachs, and Rubin, 2004).

Furthermore, the need for technology skills to use Internet-based e-health tools, such as PHRs and disease management and behavior change applications, will potentially challenge the public's capacities and further expose the limitations of current approaches.

Taking all these challenges into consideration, this study identified four requirements for a population-scale strategy for e-health tools.

1. All Americans, and especially those with the most limited health literacy, must be adequately prepared to obtain, process, understand, and apply health information and e-health tools to meet the complex information demands of the changing healthcare environment.
2. Appropriate, well-evaluated tools with adequate privacy protections and mechanisms to control access to personal health information must be widely available.
3. Diverse and underserved individuals and communities must have access to electronic resources, which includes not only the physical connection but also appropriate content.
4. Multiple stakeholders must come together to articulate and implement dissemination strategies that address the sustainability and reach of the tools across the population.

The intended audiences for this report are all the stakeholder groups discussed in the report, including policymakers, healthcare providers, public health professionals, health services and social science researchers, community-based organizations, consumer advocacy and voluntary health organizations, developers and funders of e-health tools, and consumers. This report will be successful if it draws fresh attention to the challenges of e-health as a population strategy; motivates stakeholders to contribute to the realization of the vision; stimulates collaboration and agenda-setting by stakeholder groups; and creates support for the linkage of research, dissemination, and evaluation.

## Foundations of the Present Study

The elements of the vision informing the present study have emerged over the last decade. The process has accelerated in the last few years with the release of major reports from the National Committee on Vital and Health Statistics (NCVHS) and the U.S. Department of Health and Human Services (HHS) (NCVHS, 2001, 2005b; Thompson and Brailer, 2004). New efforts focused on the promotion and deployment of PHRs as potentially transformative tools for consumers have created additional momentum (Connecting for Health, 2004). In general, these reports call for combinations of more research and joint action in the public interest. Today, the potential recognized by the earliest reports and the conditions conducive to a population-scale vision for e-health are more promising than ever. Still, many gaps remain.

McGinnis, Deering, and Patrick made the case for the public health interest in emerging information and communication technologies for prevention more than a decade ago (1995). They challenged the public health sector to contribute to building a national infrastructure that would benefit all Americans and serve primarily health, rather than commercial, interests. They described the information and communication components of prevention and connected the investment in these components to the achievement of *Healthy People* goals. The role of Government, they proposed, is to ensure that everyone has the ability to get reliable information in a way they can use. These issues became embodied in the first-ever national health communication objectives as part of *Healthy People 2010*. The *Healthy People 2010* Health Communication Focus Area includes objectives on Internet access, the quality of health Web sites, health literacy improvement, the quality of provider-patient interactions, and research and evaluation of communication programs and interventions (HHS, 2000). The communication objectives also inform and support achievement of many other objectives in *Healthy People 2010,* which number more than 400.

The Office of Disease Prevention and Health Promotion (ODPHP) of HHS and the Science Panel on Interactive Communication and Health followed this call to action with an assessment of the interactive health communication field. The Panel defined interactive health communication as the "interaction of an individual—consumer, patient, caregiver, or professional—with or through an electronic device or communication technology to access or transmit health information, or to receive or provide guidance and support on a health-related issue" (HHS, 1999, p. 8). The Panel found that national policy debates mainly focused on healthcare providers and their use of information technologies in healthcare delivery. Discussions of how consumers, patients, and caregivers would use interactive technologies to manage and improve their health were far less common.

The Science Panel identified several groups of stakeholders that, in their words, "need to participate in . . . application development, evaluation, and quality assurance if meaningful evolution and quality improvement . . . is to occur" (HHS, 1999, p. 61). Each of these stakeholder groups has its own perspectives and responsibilities as part of the process. The Panel acknowledged that, in many cases, consumers were the most "vulnerable" of the stakeholder groups because they have no common base of knowledge and abilities for using interactive health communication applications. Also, consumers typically do not have ready access to the policymaking and technology development processes, although the American Health Information Community, an advisory body to HHS, includes consumer representation and solicits consumer input.

Three years after the Science Panel issued its report, the IOM Committee on Communication for Behavior Change in the 21st Century found that although there had been rapid growth in the availability of new media, little reliable research on consumer, patient, and caregiver use of interactive health communication technologies existed in the published literature (IOM, 2002). The Committee also concluded, as had the Science Panel, that there is little solid information about how diverse users will engage with the Internet and other new technologies for behavior change or other purposes. This same theme was echoed in 2003 in the introduction to a special issue of the *Journal of Health Psychology* on e-health. The editors noted that e-health was still more promise than reality. They challenged health communication and public health professionals to use e-health technologies “to do better” than in the past to create meaningful health communication interventions that successfully change behavior and improve health (Neuhauser and Kreps, 2003). “Doing better,” they said, entails creating e-health tools that are “participatory, deeply meaningful, empathetic, empowering, interactive, personally relevant, contextually situated, credible, and convenient” (Neuhauser and Kreps, 2003). This list of attributes provides an important frame of reference for the present study.

## About This Report: Questions and Findings

This report considers “diversity” to be a key concept in the analysis of the e-health tool phenomenon. Diversity- and consumer-centered analysis suggests that in a population, there will be a range of attitudes, beliefs, values, expectations, and experience with information, technology, and health management. Methods for assessing the role of diversity engage consumers in the research process and probe those factors that shape attitudes, beliefs, values, expectations, and experiences.

In contrast, most research and funding to date have focused on individually and medically oriented technologies that emphasize individual behavior change and chronic disease management (Eng, 2004). Little attention has been paid to units of analysis—such as audiences, communities, or populations—that might be more revealing on questions of diversity, communication, and technology use.

Meanwhile, as discussed above, an environment is evolving in which most Americans will be expected to manage their health using sophisticated tools. Market and research environments are offering a host of resources, and digital technology has made possible an unprecedented level of attention to individual and community needs and interests. These developments translate into potential for improving health on a population scale using targeted e-health tools. This potential is not likely to be realized, however, if market forces or fragmented public-sector efforts are allowed to drive the e-health phenomenon.

The goal of a serious consumer e-health initiative, therefore, would be to create the conditions to enable the use of appropriate technologies to accommodate diversity, focus on end users, and promote population health. The impact and benefits of consumer e-health tools can be enhanced through a combination of creative visioning, strategy development, resource targeting, and collaboration. All efforts in this direction should take a consumer-centric approach and leverage the many interests to be served by enabling more Americans to use e-health tools.

## *Questions Addressed by the Report*

The present study was animated by five major questions relating to e-health access, availability, appropriateness, acceptability, and outcomes for diverse consumers. These dimensions for assessing the e-health phenomenon are identified in other reports (IOM, 2002; HHS, 1999). This study explored the following questions:

- What is known about population diversity that can inform the creation of appropriate e-health tools and enhance understanding of their uses?
- How is the research base for consumer-centric e-health tools evolving?
- What factors in public policy and the marketplace are influencing the development and dissemination of e-health tools?
- What gaps are not likely to be filled by market-driven solutions and should be addressed by public policy and public-private collaborations?
- What approaches exist and might be expanded to connect diverse groups of consumers with e-health tools?

The project team took a critical approach to these questions in order to get below the surface of e-health to examine gaps between promise and reality. The study identified or confirmed several encouraging trends in the consumer e-health space, many of which are familiar to observers. These trends include mounting evidence of the effectiveness of specific e-health tools, a dynamic commercial and research enterprise, a wide variety in the types of e-health tools, and creative initiatives to connect diverse communities with technologies that could be employed for health purposes. What is unique about the present study is its attention to communication and usability factors and the role of diversity as critical dimensions of evolving e-health policies, research agendas, and population-based strategies.

## *Findings of the Study*

The study generated a set of findings that highlight key areas for further analysis, discussion, and strategic action. Importantly, the conditions described in the findings are not fixed; consumer e-health is a fluid and still relatively undefined phenomenon.

**Finding 1.** Achieving broad public acceptance of personal health management and e-health tools will require greater attention to the intended users' diverse perspectives, circumstances, and experiences regarding health information and digital technologies, as well as their differing capacities for health management.

The first area requiring further analysis, discussion, and action pertains to the critical connection between the use of consumer e-health tools and the policy goal of encouraging personal health management. Personal health management is a highly information-intensive activity. At a minimum, effective "management" presumes the capacity to analyze a situation, including any available options; to define, locate, and organize necessary information in an understandable and usable manner; to apply the information to the options at hand; and to anticipate the consequences of decisionmaking. Consumer e-health tools are themselves information-intensive as a rule, and they have mechanisms to store and organize multiple types of information. Such tools provide a seemingly ideal means for consumers to deal with information demands and engage in personal health management. On the other hand, personal health management and informed decisionmaking are abstract ideals for large segments of the population because of the many barriers to accessing and using health information and services (IOM, 2004; Shaller, 2005).

In contrast, large segments of the population are savvy about digital technologies in general but largely unfamiliar with the range of e-health tools available for health management. Health information Web sites, search engines, and online support and chat groups, all of which have evolved largely outside the traditional healthcare sector, have been the main instruments of self-management for the mass of consumers. Blogs and podcasts are new forms of learning, expression, and connection among healthcare consumers (Sarasohn-Kahn, 2005). Although e-health tools are embedded in a broad shift toward a digital culture, health care as a sector has been slow to adapt to the fast-paced, user-centric world of the Internet. The healthcare sector also has been slow to develop tools that are accessible through popular media, such as cell phones and pagers, both of which have high usage that cuts across socioeconomic lines.

Consumer e-health tools and personal health management are emerging in an environment in which different orientations to digital culture have formed as consumers acquire experiences with (or avoid) other uses of the Internet. These orientations create new segments and require new ways of thinking about who will and who will not use e-health tools and for what purposes, especially when members of the population have such differing capacities to use information and technologies.

If e-health tools are to contribute to personal health management and public health in a measurable way, users and their requirements will need to be at the center of the design and dissemination process. Chapter 2 of the report explores these issues.

**Finding 2.** A large body of evidence suggests the effectiveness and utility of many consumer e-health tools. The evidence is uneven across categories of tools and user groups, however. Often, the tools are developed as research projects and not easily available in the marketplace; conversely, many tools in the marketplace do not have an explicit evidence base. Consumers may not be able to access many evaluated e-health tools that would be beneficial to their health, particularly given the increasing demands related to personal health management.

The second area calling for greater attention and strategic action concerns the apparent lack of alignment in consumer availability between those tools based on research and evaluated with intended users and those based primarily on commercial and marketing considerations. Often, the latter are tools that are widely disseminated and freely available to large numbers of potential and actual users. The situation is changing somewhat as large healthcare delivery systems integrate e-health into their normal business practices; but that form of dissemination takes place within member- or patient-based systems that are tied to clinical operations. It is a positive example, but not necessarily one that will alter the variety and quality of choices available to the population at large, especially the uninsured.

A scan of the e-health tool marketplace conducted for the present study (see Appendix 1) indicates that many well-researched e-health tools are still not easily available to the majority of consumers. Moreover, the enormous variation in features as well as the number of niche products could make it difficult for consumers to compare and evaluate competing e-health tools. When commercial tools are formally evaluated, it is typically in terms of frequency of use, usability, and satisfaction instead of effectiveness for behavior change, adherence to recommendations, or other health-related outcomes. Although some research-based e-health tools are successful in market terms, many more are not supported by business plans or other models of funding, apart from research grants, to sustain marketing, dissemination, maintenance, and innovation. Chapter 3 presents the current status of e-health research, and Chapter 4 identifies the need to coordinate evaluation and dissemination.

**Finding 3.** In addition to the lack of alignment between evidence-based and popular tools, other significant gaps include the shortage of viable and sustainable business models, the need to protect health information privacy and nurture public trust, and the need for ongoing quality assurance.

e-Health developers and researchers have identified problems caused by the shortage of sustainable business models for e-health, and they have ideas about solutions (eHealth Institute, 2002). The issues concerning business models and return on investment appear to require coordinated solutions that go beyond what the market can accomplish on its own. The important public policy goals of protecting privacy, nurturing public trust, and assuring quality also demand publicly coordinated solutions. Achieving a broader vision for e-health in the public interest will require new joint public-private efforts. Chapter 4 discusses the limitations noted here and ideas for addressing them.

**Finding 4.** The e-health arena comprises many stakeholders besides consumer end users, including healthcare organizations, purchasers, public health entities, employers, community-based organizations, and others. Many are already engaged in partnerships around funding, dissemination, research, development, and advocacy. The personal health record arena has generated early collaborations around a tool that may prove useful to diverse user groups and provide a platform for multiple e-health functions. Both coordination and Federal leadership are needed to achieve the vision proposed in this report, possibly modeled on these activities related to PHRs.

The themes of partnership and leadership emerged from the present study in ways that were not anticipated in the original study questions. Both the scan of the e-health marketplace (see Chapter 4) and the investigation of existing efforts to reach underserved communities (see Chapter 5) revealed the importance of partnerships—for example, in dissemination models in commercial and nonprofit sectors. There is something about innovation and moving beyond the status quo that seems to stimulate joining forces with other stakeholders outside customary boundaries. Discussions between the study team and a cross-section of e-health, public health, and public policy experts reinforced the importance of partnerships—especially between public and private-sector entities—to widen the effect and benefits of e-health tools.

Even when partnerships offer the opportunity to fulfill value propositions for every participant, they are not likely to occur without leadership and resources to support dissemination and use. This is especially the case when the public interest is the ultimate value sought. In that case, the leadership almost certainly must come from Government (Lansky, Kanaan, and Lemieux, 2005). The Office of the National Coordinator for Health Information Technology, in collaboration with other HHS agencies and departments in the Federal Government, is tasked with providing leadership in health information technology. Consumer empowerment is already part of the health information technology agenda and could easily accommodate the vision outlined in this report. Chapter 4 discusses some of the work of the National Coordinator's Office and that of public-private collaborations such as Connecting for Health.

**Finding 5.** Strategies for reaching diverse audiences have been developed and have proven effective in communities outside the digital and economic mainstream. These strategies could provide models for new efforts to reach diverse, often underserved, audiences, complementing more standard market approaches and widening the reach and impact of e-health tools. In addition, future e-health dissemination efforts may be able to leverage the networks they have already created.

Chapter 5 describes several innovative programs created through partnerships. As these examples illustrate, it takes a significant investment of resources and effort to create a new collaborative venture on a national or even local scale.

Chapter 5 examines the following strategies:

- Using the existing community infrastructure to provide access and training in underserved communities
    - Libraries
    - Community technology and community-based organizations
- Implementing a statewide strategy involving multiple partners
- Reaching out to target audiences
- Supporting research and development involving diverse audiences

For the most part, nonprofit and governmental bodies implement these strategies. Some of the programs profiled in Chapter 5 are already channels for e-health tools; others are potential channels. They all illustrate comprehensive approaches to achieving meaningful access. Most use participatory approaches that engage consumers not just as targets and recipients but also as co-designers of content and services. They offer sustained, continuous services at the community level and leverage significant resource commitments from a range of sponsors, including Federal agencies, industry, and foundations. All of these attributes make them important models for future e-health dissemination strategies to diverse communities.

# CHAPTER 2. MAPPING DIVERSITY TO UNDERSTAND USERS' REQUIREMENTS FOR E-HEALTH TOOLS

## INTRODUCTION

It is commonplace to observe that the United States is a diverse society and becoming increasingly so. Diversity has many dimensions including, but not limited to, cultural, economic, educational, and experiential factors (IOM, 2002). The vision for consumer e-health tools proposed in the Preface and described in the introduction (Chapter 1) emphasizes the importance of diversity and user-centric approaches.

At heart, the matter of consumer engagement with e-health tools is an issue of human communication mediated by technology, and the principles of effective communication practice must inform the design and use of tools. The strategies needed to realize the vision must be grounded in solid research on population diversity, communication, and ways that user characteristics will affect the uptake of consumer e-health tools by new groups. A more complete picture of users and the factors influencing their use of e-health tools is critical not only to the design of the tools themselves but also to meaningful metrics used to assess the tools, their dissemination, and their effects.

The need for a deep-level understanding of individual, population, and systemic factors affecting e-health tool use is acute in the context of national discussions to eliminate health disparities and improve health literacy (IOM, 2003, 2004). The health disparities and health literacy agendas make clear that critical systemic factors affect the ways people act in relation to their own health and interact with the healthcare system. These influences and their variations from person to person and from group to group have yet to be fully identified and described, and they are not adequately captured by traditional public health models and explanations that use demographic factors as the basis for communication interventions (IOM, 2002).

Digital and information disparities should be a matter of great concern for public health and medicine because many of the same segments that lack adequate Internet access and appropriate health information also have the highest risks of developing, or already have high rates of, chronic diseases (HHS, 2000). Appendix 4, A Comparison of Internet Use and Health Status of Populations That Experience Health Disparities, presents data on health disparities and Internet access. Research on consumer attitudes, perspectives, requirements, and behavior is critical to inform policies that put greater responsibility for personal health management on these at-risk population groups.

Apart from consumer surveys on trends in Internet use, little research to date has analyzed the individual and population factors most relevant for consumer e-health tools, particularly in light of personal health management requirements. Findings of this study that were culled from the scientific literature and interviews with e-health tool developers and leading observers in the field confirm that little consumer e-health research is available, particularly at the subpopulation level. Such research is necessary to inform projections of who will use e-health tools in general, or who will use specific tools, and how the use of these tools will affect their perceived and objective health status (see Chapter 3 and Appendix 1).

For the most part, the research indicates *either* who is using the Internet for health-related purposes, primarily health-information seeking, *or* how participants in research studies react to specific e-health tools. The often-overlooked elements in the overwhelming number of studies are the human factors and communication dimensions of e-health tool use. Perhaps because of the nature of online communities and the amount of personal information revealed by users, more studies in this category than any other examined in this report have explored questions of identity, beliefs, motivation, emotional and psychological states, and communication styles. (See Chapter 3.)

Even though demographic factors often provide the basis for the targeting of public health interventions, the interventions themselves rely heavily on influencing communication variables and processes as a means to produce behavior change or other outcomes. The Institute of Medicine's (IOM's) Committee on Communication for Behavior Change in the 21st Century questions demographic factors as reliable guides to understanding how individuals and groups engage in and are affected by information and communication (IOM, 2002). The Committee recommends that demographic factors be used to identify the distributions of health benefits and broad intergroup differences, but that these factors *not* be used as the basis for health communication programs and interventions. The Committee supports an approach that considers the full range of communication factors, including cultural processes, access to information and technology, and life experience.

This chapter uses that IOM recommendation as a starting point to outline a user-based approach to e-health tool design and dissemination. Some of the factors examined are demographic; others are psychosocial and communication-related. Collectively, they create a complex picture of the influences and elements that must be mapped as part of a consumer-centric analysis of the e-health tool phenomenon. Each of these factors may be more or less critical depending on the population and needs being addressed by the tool and the context in which it will be used. These factors, along with ones that have yet to be identified, provide the components for new models and strategies to reach and engage all sectors of the population and enhance the effect of a broad range of tools.

## THE HEALTH LITERACY CONSTRUCT AND ITS RELEVANCE FOR E-HEALTH

Health literacy is emerging as a powerful construct for identifying the environmental and human factors that influence the ways in which people interact with health information and the healthcare system. Health literacy is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (IOM, 2004; HHS, 2000). Literacy skills include not only reading and writing prose but also numeracy and use of different types of documents, such as forms. Individual and population health literacy is dependent on a mix of individual and systemic factors, including the communication skills of both laypersons and professionals; lay and professional knowledge of health topics; cultural factors; the demands of the healthcare and public health systems; and the demands of the situation or context. According to recent reports from IOM and the Agency for Healthcare Research and Quality (AHRQ), large amounts of existing print health information are too complex for approximately half of all adults in the United States to understand and use (Berkman, DeWalt, Pignone, et al., 2004; IOM, 2004).

Health literacy is an emerging area of study, and there has been limited reliable research on its many dimensions (IOM, 2004). Estimations of group-level health literacy capacities, for the most part, have been based on two national studies of the population's literacy skills and numerous small studies of either literacy or health literacy skills (IOM, 2004; Kirsch, Jungeblut, Jenkins, et al., 1993; National Center for Education Statistics, 2005).[1] One recent study did attempt to pool numerous small studies using multiple health literacy assessments and found that these pooled estimates were similar to the findings from the national literacy data (Paasche-Orlow, Parker, Gazmararian, et al., 2005).

Literacy skills are unevenly distributed across the population, similar to education level, income, health status, and Internet access. Literacy rates are lower among older adults and persons of lower education and income (Kirsch et al., 1993; National Center for Education Statistics, 2005). Literacy capabilities affect people who speak English as well as other languages, may impede communication of health prevention messages, and diminish the ability to participate in interventions. Literacy skills also affect how people, particularly those in underserved populations, use the Internet (Baur, 2005; Echt and Morrell, 2003; Zarcadoolas, Blanco, Boyer, et al., 2002).

Individual capacities, however, do not appear to be the most important factor in limited health literacy in a population. Health literacy problems exist in large part because the systems that provide health information and services are unfamiliar and complex, which makes it difficult for many people to understand and use them effectively (IOM, 2004; HHS, 2003). The information that health professionals have created is jargon-filled, technical, and dense; the forms and paperwork are confusing, complicated, and lengthy; and the care process and systems are cumbersome and oriented to professional requirements. As a result, few individuals are likely to ever have all the capacities needed to understand and navigate systems

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[1] The 2003 National Assessment of Adult Literacy from the U.S. Department of Education includes items on health literacy that will be used to compose health literacy scores, but the data had not yet been released when this report went to press.

### *Example of literacy and cultural factors relevant to e-health tools*

*The study subjects for our project live in a community where the level of educational achievement is low. As a result, literacy has been one of the most important characteristics of this audience affecting the design of our problemsolving e-health tool. Many of the students cannot read at grade level and have poor comprehension skills. Thus, we have had to pay particular attention to the language and reading level that our online problems feature. Simple words and short sentences are essential. If this characteristic were overlooked, then our tool would have been useless to its intended audience. . . . In addition, many of our students come from immigrant families where English is not the primary language spoken at home. We have had to recognize that some students cannot read English well, and this must be considered in designing an e-health tool that reaches all of its intended audience. Finally, minority populations often have cultural beliefs or practices regarding asthma that influence their disease management choices. We have talked with community members about these culturally based ideas and have tried to incorporate them into our problemsolving cases in order to make the experience more relevant to them.*

*Understanding the characteristics of our study population enables us to determine whether our tool is able to generate an authentic assessment of our audience's asthma knowledge and management skills. . . . [W]hen large numbers of students are not getting a problem right, it may not always mean that they are not capable. The appreciation of our audience's reading challenges enables us to realize that it can also mean that our tool is not working and has to be adjusted. This feedback from our target audience enables us to evaluate and perform ongoing refinement of the e-health tool.* (A. Casillas, personal communication, October 22, 2003)

as they currently exist. In other words, system design has created many health literacy problems, and system design must be altered to address the problems.

It appears that many of the health literacy issues that have been identified in the print environment are being transferred to the electronic arena. As noted in Chapter 3, research suggests that many Internet sites and their content are created in a style and vocabulary too complicated for many segments of the public, erecting a barrier to understanding and communication (Graber, Roller, and Kaeble, 1999; RAND Health, 2001; Zarcadoolas et al., 2002).

The commentary from Adrian Casillas, M.D., highlighted in the box above, illustrates how health literacy factors play out in the design of a consumer e-health tool. It also illustrates how literacy and cultural factors are not the same, even though they may affect the same user groups; they need to be addressed with different remedies. The vignette exemplifies the conscious and ongoing effort required of researchers and developers to understand the meaning of tools and content from the intended users' perspectives. Dr. Casillas describes the thinking behind his Los Angeles-based public health work with children with asthma, 60 percent of whom are members of Mexican and Central American immigrant families.

## THE KEY CONCEPT OF MEANINGFUL ACCESS

To use e-health tools, people obviously must own or have access to technology, including hardware, software, and Internet connections. This type of basic or physical access to technology, however, has been found to be insufficient to promote or sustain technology use among some groups of users (One Economy Corporation, 2004; The Children's Partnership, 2000, 2002, 2003). Users may not have the skills or resources they need to use technology; diagnose and solve technical problems; afford continuous service charges; or locate and understand content (Eng, Maxfield, Patrick, et al., 1998). The lack of physical access, skills, or resources creates multiple obstacles that must be identified and overcome.

Consequently, researchers and practitioners working on issues of technology access have developed the concept of "meaningful access" to encompass equipment, Internet connections, skill development, ongoing technical support, and appropriate content, all of which have bearing on the issue of a "digital divide" in society (HHS, 2003). Similarly, the health literacy construct unites the issues of capacities, access, and understanding, although it has rarely been applied to the analysis of technology use (Baur, 2005). Both concepts highlight the importance of understanding users' capacities and characteristics in light of systemic barriers that inhibit the full exercise of capacities.

Unequal access to the Internet and related technologies has been characterized as a "digital divide"; naturalistic trends toward broader access across the population and targeted interventions to increase access are described as progress toward "digital inclusion" (HHS, 2003). The health objectives in *Healthy People 2010* include an objective to increase Internet access in the home, confirming the critical nature of Internet access for the health of the entire population (HHS, 2000). Considerable progress has been made since the late 1990s, when the U.S. Department of Commerce report, *Falling Through the Net,* called the digital divide "one of America's leading economic and civil rights issues" (U.S. Department of Commerce, 1999). Nevertheless, segments of the population—primarily defined in existing studies by income, age, language, and disability—still lack access when compared to the segments with the highest rates; income is a key factor in the divide.

Table 1 reports the most current Census Bureau data on Internet access at the total and subgroup levels, using *Healthy People 2010* categories and the 1998 baseline data for the *Healthy People* Internet access objective. Since the Census findings reported in Table 1, survey research from the Pew Internet & American Life Project indicates that broadband is rapidly becoming the new

## *Table 1. Households With Internet Access*

| | Baseline, 1998[a] | 2003[b] | Broadband Access, 2003[b] |
|---|---|---|---|
| **Total Population** | | | |
| Total population | 54% | 59% | 23% |
| **Race and Ethnicity** | | | |
| Asian or Pacific Islander | 36% | 63% | 34% |
| Black or African American | 11% | 45% | 14% |
| White | 30% | 65% | 26% |
| Hispanic or Latino (of any race) | 13% | 37% | 13% |
| **Gender (head of household)** | | | |
| Female | 15% | 59% | 22% |
| Male | 20% | 58% | 24% |
| **Education Level (head of household)** | | | |
| Less than high school | 5% | 16% | 6% |
| High school graduate | 16% | 45% | 15% |
| At least some college | 31% | 69% | 24% |
| **Geographical Location** | | | |
| Urban (metropolitan statistical area) | 28% | 59% | No data available |
| Rural (metropolitan statistical area) | 22% | 57% | No data available |
| **Family Income** | | | |
| | **1997[c]** | | |
| Less than $15,000 | 30% | 31% | 8% |
| $15,000-$24,999 | 37% | 38% | 9% |
| $25,000-$34,999 | 49% | 49% | 13% |
| $35,000-$49,999 | 60% | 62% | 19% |
| $50,000-$74,999 | 72% | 72% | 28% |
| $75,000 or greater | 81% | 83% | 45% |

[a] Source: CDC Wonder. *DATA2010. . . the Healthy People 2010 Database*. Focus Area 11.1. January 2006 edition. *http://wonder.cdc.gov/*. Centers for Disease Control and Prevention. Accessed February 14, 2006.

[b] Source: U.S. Department of Commerce. 2004. *A Nation Online: Entering the Broadband Age. www.ntia.doc.gov/reports/anol/NationOnlineBroadband04.htm*. Accessed October 12, 2005. Note: The survey is conducted by household, and the data are reported as Internet access from any location by the survey respondents.

[c] 1997 data source: U.S. Department of Commerce. 2002. *A Nation Online: How Americans Are Expanding Their Use of the Internet. www.ntia.doc.gov/ntiahome/dn/nationonline_020502.htm*. Accessed March 24, 2006.

standard at the same time income divisions between broadband and non-broadband users become sharper. Total population use of broadband technologies increased to 53 percent by mid-2005; however, 71 percent of Internet users in households with annual incomes of $75,000 or higher have broadband access, whereas 42 percent of Internet households with annual incomes below $30,000 have broadband (Fox, 2005a).

As noted above, the question of access is not simply a matter of having a computer and Internet link; "meaningful access" emphasizes the factors involved in achieving genuine digital inclusion. For millions of Americans, access problems have more to do with their ability to use digital technology and the relevance and appropriateness of the information resources available to them than with their having the right equipment. These other aspects of access are gaining in importance as explanatory factors for the causes and consequences of differences in Internet use and interest among different population segments. A few studies that have examined the role of content, applications, skills, and technical support in generating and sustaining user interest found that some population segments, such as those with low income or limited English proficiency, have limited choices of relevant content (The Children's Partnership, 2000, 2002, 2003).

The most complete approaches to providing access for diverse user groups, therefore, address not only equipment and Internet access but also skill development, ongoing technical support, and appropriate content. A report from the Kaiser Family Foundation expresses the same ideas by distinguishing between *quantity* and *quality* in Internet access (2005). Being connected to the Internet has little meaning in itself if users cannot find relevant content and services. Specific aspects of meaningful access related to audience characteristics are discussed below in this chapter, and Chapter 3 explores the subject in light of existing research on the appropriateness of content.

Although national surveys of Internet access and use provide little detail on the public's perceptions of technology, some findings suggest diverse attitudes toward, and likely capacities with, technology. Although Internet penetration has increased to its highest levels yet, about 25 percent of the population are not online, primarily because they do not have a computer (University of Southern California [USC] Annenberg School Center for the Digital Future, 2004). Studies suggest that cost is only one obstacle, and not always the most important one, to computer ownership and Internet use. The USC Digital Future study found that only 9 percent of respondents not connected to the Internet reported the cost of technology as the reason. An additional 24 percent reported that they had no interest in being on the Internet, and another 18 percent said they did not know how to use the Internet (USC Annenberg School Center for the Digital Future, 2004).

A small study in San Diego, California, found that psychosocial factors, such as embarrassment at not knowing how to use a computer, were more important than cost in explaining why low-income residents did not purchase computers or were not learning how to use computers at local community centers (Stanley, 2001). Moreover, in this same study, residents reported ownership of other types of technology, such as DVD players and cell phones, which suggests that their concerns were specifically with computers and not technology in general. Research from the Pew Internet & American Life project supports this finding with data showing that technology gaps by racial group and age are not as great for cell phones as for computers (Fox, 2005a).

As noted in the preceding health literacy discussion, a few small studies suggest that persons with limited literacy skills are likely to be among those who do not know how to use the Internet without training and support. The U.S. Department of Education investigated associations among literacy skills, Internet access, and computer use for the first time as part of the 2003 National Assessment of Adult Literacy; results will be released in the second half of 2006 (see *http://nces.ed.gov/naal/*).

Access to Internet-ready devices such as cell phones and Personal Data Assistants (PDAs) can remedy the lack of a computer. However, the attitude that Internet access is not necessary for daily life may itself become an important source of social division, according to Jeffrey Cole, Director of the USC Annenberg School Center for the Digital Future. He notes that people who live daily life disconnected from the Internet may face real costs—financial and social—not simply inconveniences: "People who do not want to perform those chores (pay bills, send letters, make appointments, and so on) online will find it increasingly difficult and expensive to avoid doing so" (Cole, 2004).

As an increasing number of health plans, employers, and healthcare providers develop Internet-based resources, their beneficiaries, employees, and patients will have fewer real choices about receiving information and services in a nondigital form. Beneficiaries, employees, and patients who do not have Internet access or choose not to use it will find that either they do not have access to vital information and services or they have to rely on intermediaries who will use these technologies on their behalf. The emergence of broadband as a new standard for connectivity and the dependence of multimedia applications, including most e-health tools, on broadband are already creating additional disparities. Broadband makes it more likely that people will use the Internet and for longer periods, which are requirements if people are going to incorporate e-health tools into their routines.

Learning more about the one-quarter of the population who may become isolated by their attitudes toward digital technologies and the options that will be required to continue to serve them is an emerging research and policy issue. Intermediaries or "infomediaries" have been suggested as a solution for some users who do not want to seek out information themselves or use technology directly; this strategy assumes, however, both that the intermediaries have the necessary access and skills and that they are available when and where users need them. These assumptions raise multiple issues for policymaking that future studies should address.

## USER BEHAVIOR AND HEALTH INFORMATION-SEEKING

Although health is only one reason people use the Internet, approximately 95 million American adults have used it to find health information, most to seek information on a specific disease or medical problem (Fox, 2005b). About one-half of Internet users accessed healthcare information in 2004 (USC Annenberg School Center for the Digital Future, 2004). Experienced Internet users (those with 6 or more years of experience) are far more likely to have used the Internet as a source of health or medical information in the last year than new users (those with fewer than 2 years of experience) (Fox, 2005b; USC Annenberg School Center for the Digital Future, 2004).

Similar to the data on interest in the Internet, these data suggest that long-term Internet users are likely to have integrated the technology in their lives across a broad set of purposes; those new to the Internet may be in the process of discovering purposes for use. Yet, both new and experienced users express similar levels of confidence that they could find health or medical information on the Internet if they needed to (Fallows, 2005; USC Annenberg School Center for the Digital Future, 2004). Although these findings suggest a strong sense of self-efficacy across user groups and perceived value of available information, they do not address different segments' understanding of and capacities to apply information.

As evidenced by the number of published studies in the peer-reviewed literature, there is a great deal of interest in who is using the Internet to search for health information and for what purposes. The Pew Internet & American Life Project has conducted extensive survey research on the public's online habits and behaviors, including search behaviors and health information-seeking (for examples, see Fallows, 2005; Fox, 2005b). The Pew Project finds that search engines are the overwhelming favorite method to find information on the Internet; 84 percent of Internet users chose search engines to locate the information they seek (Fallows, 2005).

Table 2 summarizes selected peer-reviewed research studies from the journal literature on Internet health information-seeking. The studies typically were designed to identify relevant factors of use by different audience or user segments. These studies have some utility as guides to the attitudes and interests of different audiences and users, although in most cases the findings are descriptive rather than analytical or explanatory. In general, these studies are most useful to describe how often different groups search for different types of health information and the utility or value of the information for their specific needs. Although the location from which people access the Internet was of interest in the present study, only two research studies included information on this variable (Borzekowski and Rickert, 2000; Smith-Barbaro, Licciardone, Clarke, et al., 2001).

Indicators suggest that many segments of the population are ready to think about new uses of digital technologies for health. Connecting for Health, a public-private collaborative to promote the use of health information technologies, conducted

*Table 2. Selected Peer-reviewed Research Studies on Internet Use, Searching Behaviors, and Users' Attitudes and Interests*

| Study | Population Group | Sample Size | Descriptive Variables |
|---|---|---|---|
| Baker, Wagner, Singer, et al., 2003 | Adults | 4,764 self-reported Internet users | Frequency; E-mail with physician; Impact on health decisions and utilization; Online purchasing |
| Borzekowski and Rickert, 2000 | Urban adolescent girls | 176<br>— 86 from private high school<br>— 90 from low-income clinic | Frequency; Topics searched for; Value; Comfort |
| Borzekowski and Rickert, 2001 | Suburban high school students | 412<br>socioeconomically and ethnically diverse | Frequency; Topics searched for; Value |
| Bull, McFarlane, and King, 2001 | Internet users | 4,601 who completed online survey of sexual risk behavior | Topics of interest; Functions of interest |
| Diaz, Griffen, Ng, et al., 2002 | Primary care patients | 1,000 randomly selected patients | Demographics; Topics; Quality; Consult with physician |
| Dutta-Bergman, 2003 | Nationally representative sample | 2,636 respondents to Porter Novelli HealthStyles survey | Demographics; Trusted sources of information |
| Feil, Glasgow, Boles, et al., 2000 | Primary care patients with type 2 diabetes | 160 | Willingness to enroll in Internet-based diabetes self-management |
| Houston and Allison, 2002 | Internet users who go online for health information | 521 (Pew sample) | Demographics; Health status; Functions of interest; Infomediaries; Consult with physician |
| Kalichman, Benotsch, Weinhardt, et al., 2002 | People living with HIV/AIDS | 259 men and women recruited from infectious disease clinics and community-based AIDS services | Demographics; Knowledge; Self-efficacy |
| Kalichman, Benotsch, Weinhardt, et al., 2003 | HIV-positive persons | 147 | Knowledge; Coping; Social support |
| Monnier, Laken, and Carter, 2002 | Patients with cancer and caregivers | 319 in waiting rooms of medical university cancer center | Demographics; Interest in topics; Interest in locus of use; Intent to use |

*Table 2. Selected Peer-reviewed Research Studies on Internet Use, Searching Behaviors, and Users' Attitudes and Interests (continued)*

| Study | Population Group | Sample Size | Descriptive Variables |
|---|---|---|---|
| Morrell, Mayhorn, and Bennett, 2000 | Adults age 40 and older | 550 adults in Michigan | Frequency; Topics of interest; Reasons they do not use |
| Pandey, Hart, and Tiwary, 2003 | Adult women | 1,016 women in New Jersey | Reasons to use |
| Peterson and Fretz, 2003 | Patients with lung cancer | 139 patients in university hospital cancer clinic | Demographics; Source of information comparison; Quality |
| Rideout, 2001 | Generation Xers | 1,209 young people age 15 to 24 | Frequency; Activities; Influence; Behavior |
| Safran, 2003 | Parents | 300 Medicaid parents with infants in intensive care | Frequency; Barriers |
| Sciamanna, Clark, Houston, et al., 2002 | Primary care patients | 300 patients from community-based primary care practices<br>— 109 without Internet access<br>— 191 with Internet access | Demographics; Interest in topics; Experience with different functions |
| Semere, Karamanoukian, Levitt, et al., 2003 | Parents | 150 primarily female parents of surgery outpatients | Demographics; Frequency; Assessment of information; Impact of information |
| Smith-Barbaro et al., 2001 | Family medicine patients | 824 patients in university-based family practice clinics | Demographics |

research on public opinions and attitudes about personal health records. The researchers found that although two-thirds of the public had thought very little about accessing their personal health information on the Internet, about half thought that they would like to try it. The study found that, in general, "people often do not consider electronic solutions to their personal health information management needs" (Connecting for Health, 2004, p. 47), but a large number of persons under age 65 are ready at least to consider the idea. One study in Queens, New York, found that a low-income, ethnically diverse patient population reacted very favorably to the use of "smart cards" for basic personal health records (Versel, 2004). Surveys find that e-mail for clinician-patient communication could be a popular use of the Internet, if clinicians were more willing to use it. A *Wall Street Journal*/Harris Poll finds that although only 8 percent of adults report using e-mail with their physicians, 81 percent either strongly favor or somewhat favor doing so (The Wall Street Journal Online, 2005).

## User Characteristics That Influence e-Health Tool Use

Public health interventions typically rely on broad demographic categories to identify who is affected by an issue, risk factor, or disease. Those most affected become the targets for an intervention. These demographic categories—including race, ethnicity, gender, age, income and education levels, and disability status, among others—are the basis for much of the current debate on the nature and extent of health disparities (HHS 2000, 2005a).

One of the original purposes of the present study—a purpose that could not be wholly fulfilled because of a lack of existing research and publicly available data—was to identify and analyze factors in addition to demographics that affect the adoption of e-health tools by those population segments most affected by health disparities. As noted throughout the report, studies suggest that populations that experience health disparities are also likely to experience disparities in technology access and use. Beyond these broad observations, however, little information addresses factors related to users' motivation, engagement, and understanding of e-health tools and their relevance to strategies to promote greater use. The IOM Committee on Communication for Behavior Change in the 21st Century found that "data that provide a much deeper and more sophisticated understanding of how specific beliefs and behaviors and health status covary across the U.S. population and of how health behavior is shaped by sociocultural processes are not available. . . ." (IOM, 2002, p. 15).

Demographic characteristics or functional skills, such as low literacy, novice computer skills, and limited English proficiency, are the main factors that have been used to characterize user groups to date. Gender, education, income, and age are strong determinants of interest and behavior in health information-seeking across media, according to a review of prevention communication and media use (Lieberman, Benet, Lloyd-Kolkin, et al., 2004). Regardless of ethnicity, well-educated, affluent women under age 65 are the most active health information consumers.

Studies suggest that race and ethnicity have some association with communication processes, perhaps because of the ways that race can act as a marker or proxy for cultural factors. The literature review conducted for this study (see Chapter 3) found that few studies explicitly assessed the significance of race, ethnicity, or culture on participants' interaction with and response to technologies. A few studies did recruit participants on the basis of racial and ethnic characteristics, but they did not explore the significance of cultural influences.

Race and ethnicity are highly significant variables for health status, if only because of the impact of discrimination on health disparities. However, there is often more variation within traditional demographic categories than between them. Moreover, the IOM Committee on Communication for Behavior Change in the 21st Century cautions that the use of overly broad or rigid demographic characteristics can actually exacerbate inequities by reinforcing inaccurate assumptions and stereotypes. This Committee calls for a focus on "more meaningful ways of describing heterogeneity," focused on cultural processes, life experience, sociocultural environment, economic contexts, community resources, and beliefs (IOM, 2002).

From a communication perspective, people attribute meaning and make sense of the messages, interactions, situations, and media around them; and they interact with and shape both the tools and the environments in which they live. Interactive media, including e-health tools, make these processes more obvious because they provide new opportunities to act as engaged users instead of passive receivers of information, "link(ing), think(ing) and interact(ing)" with information and other users (Cole, 2004). Individuals become involved in shaping an environment of highly personalized and private engagement with the Internet, Web sites, and interactive components.

Some researchers conceptualize the Internet as a "hybrid" medium with features of mass and interpersonal communication (Cassell, Jackson, and Cheuvront, 1998). Some of the many communication factors relevant to the analysis of e-health tools are patterns of media or technology use, values, beliefs, intentions, expectations, preferences, perspectives, capacities, and access to information and technology (Neuhauser and Kreps, 2003). The characteristics of technology are important in terms of its fit with, value for, and usability by different user groups (Badre, 2002; Nielsen, 1999; Norman, 2002).

The lack of research on psychosocial variables other than health information-seeking as well as the lack of multivariate analyses of demographic and communication factors are major gaps in the literature (Lieberman et al., 2004). A few studies have examined the motivations or level of interest of potential or actual users of e-health tools—typically health information Web sites, online communities, or provider-patient e-mails. It is easier to know who, in demographic terms, is or is not using computers and the Internet than it is to know how individuals think about what they do online and how the interaction reinforces or changes their attitudes, beliefs, values, and preferences.

Despite the paucity of research, however, some things are known about factors that influence health communication processes and audiences' interactions with media. The most influential characteristics that have some evidence of their relevance are discussed briefly below.

### *Language Spoken*

The relevance of language spoken to the use of e-health tools cannot be overstated. If individuals or groups use one language and the tool is based on a different language, users are very unlikely to make sense of the tool and the content. English-language materials dominate the Internet, which limits the utility of the content for those who read little or no English (The Children's Partnership, 2000).

Approximately 19 percent of the population speaks a language other than English, according to 2004 Census Bureau data (U.S. Census Bureau, 2004). The majority of persons in this category are Spanish speakers (62 percent); Chinese is a distant second. Data from the Census and the U.S. Department of Education suggest that the majority of persons who speak a language other than English at home consider themselves able to function "very well" in English (Greenberg et al., 2001; U.S. Census Bureau, 2000). Overall, the Census Bureau reports that 92 percent of the population over the age of 5 years report that they do not have difficulty functioning in English (U.S. Census Bureau, 2000). Census data indicate that approximately 4 percent of the population is "linguistically isolated" (U.S. Census Bureau, 2000). Despite this picture of English-language functioning, these data do not speak to issues of language preferences of different groups, the significance of language as an element of culture, or the role of language in perceptions of health and illness.

"Linguistic appropriateness" may seem straightforward, but it is not. Fulfilling the proviso that communication should be in the primary language of the target audience is not simple for large and diverse population groups, given the number of versions of a given language. For example, Spanish speakers present an interesting example of the complexities of linguistic appropriateness. This population segment is both culturally and linguistically diverse, coming primarily from multiple countries in Latin America and the Caribbean and with distinct cultural origins related primarily to Africa, indigenous America, and Europe. Despite the cultural relevance of slang, dialect, and vocabulary, there is often an imperative to identify a "common" Spanish that will function cross-culturally (Schroeder, Trowbridge, and Price, 2002). One of the few general studies of factors relevant for Hispanic groups' use of the Internet found that Hispanics encounter many barriers when trying to locate Spanish-language health information online (Schroeder et al., 2002).

At the same time, market research reports on Hispanics' Internet use indicate that they are going online faster than any other segment and are finding content of interest in the categories of communication (e.g., instant messages), entertainment (particularly music), and product information (*Hispanic Market Weekly,* 2006). When they perceive the relevance of the content, Hispanics are willing to go online to "compare prices, see features, learn about benefits, and then decide on a brand or purchase," according to the publisher of *AOL Latino* (cited in *Hispanic Market Weekly,* 2006).

Small-scale studies of the health information needs and preferences of Asian Americans, Native Hawaiians, Pacific Islanders, and Native Americans suggest that lack of content in the first languages of ethnic groups and inexperience with Internet resources are major barriers to greater use (Hsu, 2003a, 2003b). However, these factors have yet to be analyzed in terms of their contribution to overall lower rates of Internet usage and demand for e-health tools. For example, in a national survey of unpaid caregivers, only 5 percent reported that "finding non-English educational materials" was an unmet need (National Alliance for Caregiving and AARP, 2004).

In the scan of e-health tools conducted for this report (see Appendix 1), language and literacy emerged as two critical considerations in the design of successful tools. Even if developers did not report using any other methods to account for audience variations, they did mention creating understandable materials as design and content priorities. Designing for a stated reading grade level seemed to be the most popular strategy to make content more understandable. Providing content in Spanish was the most popular alternative to English.

Both these strategies have their own problems and raise a number of issues concerning the utility and comprehensibility of content. Even when content developers attempt translation, the quality of translations and the readability of materials can present problems. For example, translations can be of poor quality and reproduce problems, such as jargon and unfamiliar terms, that were features of the original text. Texts that meet a stated reading grade level can still make it difficult for users to understand the core meaning. Applying a health literacy approach that engages intended users in the development of the content from the beginning and focuses on assessing usability and understanding seems the most promising mechanism to address issues of language and literacy.

## *Socioeconomic Position*

IOM proposes that the most important forms of diversity to pay attention to in health communication are those associated with "substantial disparities in health status and outcomes" that also represent differences in "health behavior and its antecedents" (IOM, 2002, p. 7). Individually and collectively, the components of socioeconomic position—including income, employment status, wealth, education, housing, and neighborhood environment—influence health, health behavior, and factors involved in health communication. IOM's *Promoting Health* report discusses the relationships among these factors (2000). Communication theory from the 1970s proposed the existence of a "knowledge gap," which represents the divide between higher socioeconomic persons who pay closer attention to and have greater access to information than lower socioeconomic persons (Tichenor, Donohue, and Olien, 1970). In the e-health arena, socioeconomic factors are major determinants of the elements of meaningful access, as discussed above.

Preliminary analysis of national data from the Health Information National Trends Survey, conducted by the National Cancer Institute (NCI), suggests that income and education levels, as well as gender and age, strongly influence the amount of attention people pay to health topics (Hesse, 2003). A study by Tu and Hargraves indicates that level of education is the most important predictor of health information-seeking; 55 percent of people with postgraduate education said they sought health information, compared with only 25 percent of those without a high school diploma (2003). Education level is also strongly associated with literacy skills, which are a component of health literacy. The relationship between education and literacy likely goes both ways: those who stay in school longer likely have stronger literacy skills, and those with stronger skills likely stay in school longer. This relationship indicates that there is much to learn about how both education and literacy affect people's access to, interest in, and engagement with health information and the pathways for development of communication capacities.

### *Disabilities*

An estimated 54 million Americans—20 percent of the population—have disabilities (HHS, 2000). Disability, by definition, involves the interaction of impairments and environmental barriers; removing or reducing a barrier can reduce a disability. The types of impairments can include visual, hearing, mobility, cognitive, and learning disabilities. Each type of impairment corresponds to a set of accommodations needed to reach a particular audience segment with effective e-health resources. Disabilities affect people of all ages, but the proportion of the population affected increases with age; therefore, because the U.S. population is aging, the proportion of Americans with disabilities is growing (HHS, 2005b). There are many crossovers between the topics discussed in this section and those on the characteristics and communication needs of older adults and family caregivers, described below. Although people with disabilities are not necessarily in poor health, they are at increased risk of secondary conditions and may have less access to health services and medical care. Health promotion to improve functioning and reduce the incidence of secondary conditions has been shown to be effective (HHS, 2000).

A report by the Pew Internet & American Life Project includes a "special analysis" on Americans with disabilities (Lenhart et al., 2003). The research shows that 38 percent of Americans with disabilities use the Internet, compared to 58 percent of the entire population. Users with disabilities are more likely than the general population to have access only at home (58 percent versus 44 percent, respectively) as well as more likely to look for medical information online (75 percent versus 59 percent, respectively). The Pew research also yielded insights into the reasons persons with disabilities give for not going online—some of which, such as misconceptions about the Internet, are amenable to solution (Lenhart et al., 2003).

For people with disabilities, digital divide issues apply not only to Internet access but also to a broad set of assistive and adaptive technologies that increase accessibility of all kinds. Some of these technologies, which have been likened to "electronic curb cuts," enable access to the Internet and other digital resources for people with disabilities. Physical barriers to Internet use—or, alternatively, accommodations—can exist at many points, including the public access computing site, the computer terminal, the Web site, the Internet service provider, the browser, and the Web-based platform. Designing for persons with impairments was rare in the 40 e-health tools reviewed for this report (see Appendix 1). Only one makes specific accommodations for people with hearing or visual impairments.

Once physical access to computers and the Internet is achieved, the next set of issues relates to the design, content, and delivery of digital information resources. Paradoxically, although the Internet can reduce the isolation that can come with disability, it also presents its own barriers that must be overcome before it can be useful. The specific barrier, and thus the solution, varies with the impairment, and a detailed review of the often quite technical ways to achieve accessible Web design is beyond the scope of this brief overview. The creator of cascading style sheets, one such mechanism, points out that Web-based information involves the interaction of "content and presentation," and these have to be addressed separately in order to successfully communicate with people with visual and hearing disabilities (Bartlett, 2002).

The types of accommodations in content and presentation for people with disabilities can be beneficial to other e-health audience segments as well, such as seniors and people with limited literacy or English proficiency. The accommodations include multimedia presentation, breaking text into small chunks, and allowing users to control font size and other visual attributes. Techniques such as these, together with general principles of user-centered design and usability testing (described below), can result in e-health resources that are beneficial to all people, including those with disabilities.

The problem of inadequate research to guide design and content decisions figures in this context as it does elsewhere. Apart from the few references noted above, the present study found no empirical research on health communication issues for people with disabilities. This finding was confirmed by staff members of the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, who conducted an unsuccessful literature search on health communication and disability in preparation for a health promotion campaign for women with disabilities (J. Thierry, personal communication, October 2004).

Developers can draw on a combination of laws, guidelines, and evaluation tools in achieving and measuring accessibility. Federal law on accessibility is in Section 508 of the 1973 Rehabilitation Act (revised based on the Americans With Disabilities Act), which requires that Federal agencies' electronic and information technology be accessible to people with disabilities. An article in the *Journal of Medical Internet Research* reported on research that evaluated 108 Web sites for consumer health information according to disability accessibility guidelines; the researchers found that Government and educational sites are the most accessible, presumably at least partly because of Section 508 requirements for Government sites (*www.section508.gov/*). No site met all the criteria, however (Zeng and Parmento, 2004). Although the requirements only apply to Federal sites, some private Web developers choose to comply as well. (See Chiang and Starren, 2004, for another published evaluation of Web access for people with disabilities).

The World Wide Web Consortium (W3C) Web Accessibility Initiative has developed its own Web Content Accessibility Guidelines (WCAG) for determining Web page accessibility (*www.w3.org/WAI/*). The Web site of the International Center for Disability Resources on the Internet leads to a long chain of useful resources (*www.icdri.org/prodserv.htm*). The same is true of "Bobby," a Windows-based tool that provides a free service to analyze Web pages for their accessibility to people with disabilities, to identify and repair barriers to accessibility, and to facilitate compliance with accessibility guidelines such as Section 508 and W3C's WCAG (*http://webxact.watchfire.com/*). One expert reports that current Web accessibility guidelines do not address cognitive disabilities very well, as most of the focus to date has been on visual and sensory disabilities (R. Appleyard, personal communication, October 2004, citing Wehmeyer, 1998, 1999).

### Age, Developmental, and Role Issues

As noted above, age is one of the most important factors affecting health status, information-seeking, media use, and Internet behaviors. Yet little attention has been paid to life course, roles (apart from parenting), and experiential variables that are often associated with age. Each phase of life has its own developmental perspective, obstacles and facilitating factors, and unique experiences that influence interests and capacities related to health communication. For example, unpaid caregiving by adults for adults is emerging as a critical policy issue as well as an experiential factor for millions of Americans. A survey by the National Alliance for Caregiving and AARP estimates that approximately 44 million adults provide unpaid care to other adults (National Alliance for Caregiving and AARP, 2004). The survey finds that "the typical caregiver is a 46-year-old woman who has at least some college experience and provides more than 20 hours of care each week to her mother." Approximately one-third of caregivers rely on the Internet for information to help them cope with their caregiving (National Alliance for Caregiving and AARP, 2004, p. 68).

Internet use is inversely associated with age. Only 22 percent of people older than age 65 have been online (Fox, 2004), compared with 96 percent of children and adolescents age 8 to 18 (Rideout, Roberts, and Foehr, 2005). The higher percentage of young people online is to a great extent due to school-based access, whereas home access remains a concern for the large segment of low-income children. Home-based access is also important for older adults, who are more likely to be out of the workforce or homebound. Partly because of young people's greater exposure to technology, training, and technical assistance opportunities, they show greater comfort and facility with technology than older adults. (Indeed, some programs involve them as trainers, as seen in Chapter 5.) Older adults are more likely than persons in other age groups to have physical or cognitive impairments that further limit their ability to use computers and navigate the Internet (Morrell, Dailey, Feldman, et al., 2003; SPRY Foundation, n.d.).

However, both groups have shown considerable interest in health topics. Older adults use their Web access for health purposes more intensively than other age groups (Fox, 2004); and 68 percent of 15- to 24-year-olds and 50 percent of all 8- to 18-year-olds who have been online have used the Internet to get health information (Kaiser Family Foundation, 2001; Rideout et al., 2005).

One study is suggestive about the relationships among age, experience with both health and technology, and use of e-health tools. It examined participation and nonparticipation rates by primary care patients with type 2 diabetes in an Internet-based diabetes self-management support program (Feil, Glasgow, Boles, et al., 2000). The researchers found no significant differences in gender, insulin use, computer familiarity, or computer ownership. The significant differences between participants and nonparticipants were related to age and years since diagnosis; younger patients with more recent diagnoses were more likely to participate.

A relatively recent development of special relevance for older adults, including the significant percentage who are caregivers, is the growing use of disease management tools by healthcare organizations. Older adults have the largest incidence of costly chronic illnesses, and major institutions such as the Centers for Medicare & Medicaid Services (CMS) and the U.S. Department of Veterans Affairs (VA) are investing in the development of e-health tools to help patients manage their diseases. These programs provide training and sometimes the necessary equipment. If this trend continues, at least a small segment of older adults may be induced to become users of electronic communication and information for personal health management. In addition, the Web portal being developed for Medicare beneficiaries introduces them to an e-health tool that contains content of direct relevance.

Although the specifics vary considerably, both older and young age groups have style preferences, technology use characteristics, and health content interests that are often not served by standard e-health tool content, design, and architecture and that are best accommodated through targeted tools. The top priorities for meeting the needs of older and younger users include simplicity of design and content and the use of multimedia presentations. One example of applying good design practices and research-based knowledge of intended users is the Web site for older adults sponsored by the National Institutes of Health (*www.nihseniorhealth.gov*). The site is designed to accommodate limited literacy levels, cognitive and physical impairments, and different modes of learning (e.g., textual, visual, auditory). The Web site's approach closely matches the general principles of good Web design for all users promulgated by the Federal Government (see *www.usability.gov* and *www.firstgov.gov/webcontent*). Many e-health tools designed for young people have behavior change and prevention purposes; here the challenge is to make them interesting and attractive.

### *Interest in Health Information*

Health information-seeking attitudes and behaviors, as well as attitudes and behaviors toward health care and healthcare providers, have been identified as a useful basis for segmentation with respect to e-health communication. Researchers and expert observers classify people in terms of their degree of independence and initiative in relation to health care and health information-seeking. For example, research by the communication firm Porter Novelli found that the public can be segmented into five health information types, based on two broad sets of characteristics—degree of reliance on physicians for health information and level of activity in seeking out such information (cited in Lieberman et al., 2004).

- **The Uninvolved** (14 percent) are likely to describe their health as good or fair; value health less than others do; expend less energy on prevention; and exhibit low interest in health information.
- **Doctor-Dependent Passives** (20 percent) describe their health as excellent or very good; hold lower values for health and prevention; and express low interest in health information.
- **Moderates** (28 percent) are generally healthy adults; value good health and actively try to prevent disease; and value health information, but do not enjoy searching for it and may lack skills to do so.
- **Doctor-Dependent Actives** (20 percent) value health and prevention, but experience more health problems; and actively seek health information and are capable of finding it, but may have difficulty interpreting it.
- **Independent Actives** (19 percent) are in very good health; highly value health and prevention; place the highest importance on health information; and are very skilled at finding and understanding health information.

Long-time online health activist and analyst Dr. Tom Ferguson proposes a new vocabulary to capture the shift in individuals' orientation to information and their health. Instead of "consumers" or "patients," he sometimes speaks of "medical end users," "e-patients," and "prosumers," the last term coined by Alvin Toffler in *The Third Wave* to capture the blurring of the distinction between service providers and recipients (Ferguson, n.d.). Similar to the Porter Novelli categories, Ferguson divides patients and consumers into three groups—passive patients, concerned consumers, and health-active prosumers—and he predicts an increasing shift into the third group. In addition to information, he stresses the importance of communication among consumers, such as in online and face-to-face support groups.

Dr. Judith Hibbard has developed a multifaceted typology to assess levels of "health activation" in patients and consumers (Hibbard, 2003).[2] Her work primarily concerns health behaviors, but it is highly relevant to health information-seeking and use. Hibbard's "activation measure" assesses patients along two axes, one listing actions the individual can take related to personal health and the other listing the capacities to be assessed with respect to those actions (Table 3).

Hibbard states that consumers with higher activation are more likely to take such actions as read about possible complications when taking a new medication, seek out health information, visit a health Web site, and know about treatment guidelines for their condition. The relevance of her work for the present report is summarized in two questions she poses:

- What kinds of strategies will be most effective in increasing activation?
- How can we take advantage of knowing a patient's activation level to tailor an intervention?

### *Attitudes About Privacy and the Protection of Personal Health Information*

Since the initial framing of this project and drafting of the report, the issues of protecting personal privacy and ensuring the confidentiality of personal health information have moved to the top of the agenda in any discussion of consumer e-health tools, particularly personal health records. Numerous documents assert that there must be strong privacy protections for e-health tools that collect and store personal health information; the need for

*Table 3. Domains for Measuring Activation Measure*

| | . . . self-manage | . . . collaborate with provider | . . . maintain function/ prevent declines | . . . access appropriate and high-quality care |
|---|---|---|---|---|
| Has the knowledge to: | | | | |
| Has the skills to: | | | | |
| Can access emotional supports to: | | | | |
| Believes patient is important in: | | | | |

Source: Judith Hibbard, Dr.P.H., University of Oregon. Slides presented at Center for Information Therapy conference, September 2003.

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[2] This discussion is based on several of Dr. Hibbard's articles and on her slides, "Measuring and Improving Patient Activation," for a presentation to a September 2003 conference of the Center for Information Therapy. *www.informationtherapy.org/conf_mat03/final_pres/Hibbard.pdf*.

strong protections has been particularly noted in relation to personal health records (Markle Foundation, 2005; NCVHS, 2005a). Several national surveys have been conducted to gauge public understanding of privacy issues and the public's expectations about privacy protections in an e-health environment (California HealthCare Foundation, 2005; Markle Foundation, 2005; Westin, 2005). The findings are consistent that a majority expect strong privacy protections, whether through policies, laws, or technologies.

The findings of two surveys suggest, however, that as in most other areas, segments of the public can be distinguished on the basis of their attitudes toward privacy, and likely by their privacy-protecting behaviors as well (California HealthCare Foundation, 2005; Westin, 2005). As with other factors discussed in this chapter, attitudes about health information privacy and e-health tools have not been well studied. It is possible to infer from user behavior in online communities, however, that participants do not perceive all disclosures of personal information as equal. Participants often post highly personal and identifiable information in online chats and blogs; yet a disclosure of the same or similar information as a result of a security breach of a digital record system would likely be treated as a privacy violation.

In numerous hearings on personal health records, the National Committee on Vital and Health Statistics consistently heard testimony that the key factor for consumers is their ability to control their own information and records and protect their privacy (NCVHS, 2005a, 2005b). In light of the preceding discussion on the diversity in information-seeking behaviors and activation toward health, the need for control and sensitivity to disclosures also should be treated as having a range of values rather than dichotomous values of either total or no control and sensitivity to disclosure of personal information.

## Designing for Diverse User Groups

Given the number of factors that must be considered when designing tools to meet the needs of diverse users, it is clear that a focused effort by developers is required. Engaging persons with low income or education, different ethnic groups, and adults with limited literacy skills in health communication requires sophisticated audience segmentation techniques that involve intended users of the information in interactive roles (Freimuth and Mettger, 1990). Targeting (audience segmentation) and tailoring on communication factors are considered promising strategies for user-centric design in the electronic environment (IOM, 2002). Both are employed to engage users by personalizing and individualizing information based on demographic, behavioral, motivational, psychosocial, or physical characteristics (Brug, Oenema, and Campbell, 2003).

Targeting or audience segmentation is selecting groups of users based on common characteristics related to behavior, health status, or some other common factor. The process of targeting generally happens in the following sequence. First, a target audience or market is identified, related to a healthcare or public health need or a business opportunity. Then, the audience is analyzed, and if necessary, segmented, to optimize service and impact. In some cases, specialized products and services are developed for existing audience segments or new target audiences. Some tools integrate tailoring capabilities that make it possible to accommodate individual differences. This sometimes involves "cultural tailoring," or tailoring to enhance the impact for individuals in targeted audience groups (IOM, 2002).

Tailoring is designed to simulate personal counseling in that the individual is surveyed and the responses are used to generate individualized information and feedback (Brug et al., 2003; IOM 2002).[3] Tailored information has been shown to be more satisfying, read more deeply, seen as more personally relevant, and more often discussed with others (Brug et al., 2003). "First-generation" tailoring involves using a computer program to generate the individualized feedback that is presented to the user in a print-based format, such as a letter or newsletter. "Second-generation" tailoring takes advantage of the computer's ability to immediately deliver tailored information and eliminates the lag time incurred while waiting for printed, tailored information to be presented (Oenema, Brug, and Lechner, et al., 2001).

Dr. Victor Strecher and Dr. Kevin Wildenhaus at the University of Michigan are leading practitioners of computer-based tailoring in health communication. They prefer tailoring over targeting to enhance the effectiveness of health communication messages. When asked to identify the intended user groups or populations served by the e-tools his lab develops, Dr. Strecher stated, "Targeted messages miss the important variation in behavioral predictors that are often found within demographic or even psychographic groups. Tailoring identifies these predictors at an individual level and addresses them." He further stated, "Our most recent research suggests that deeply tailored materials seem to help the people who need them the most—those with low perceived capabilities in solving problems on their own. Tailoring may particularly help these individuals by providing a very individualized plan and by conveying information in a more vivid manner" (V. Strecher, personal communication, March 16, 2006). The National Cancer Institute (NCI) has funded Dr. Strecher's lab to work on identifying the "active ingredients" that make computer-based tailoring successful.

Enhancing the usability of Web sites is another strategy to make e-health tools more fully accessible to all users (Koyani, Bailey, and Nall, 2003). In the Government context, the HHS Web team and NCI have played a leading role in developing and implementing a usability approach to improve the navigation of Web sites (*http://usability.gov*). Usability testing can be used on its own or as part of a broader approach known as user-centered design.

User-centered design is an iterative process that assesses tools throughout the design life cycle in terms of users' preferences and performance. The process includes task and user analysis and participatory methods, such as focus groups and surveys, to determine the interests and capacities of

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[3] For a book-length treatment on computer-based tailoring, see Kreuter, Farrell, Olevitch, et al., 2000.

prospective users. Later, usability testing determines how well users are able to use a given tool, with the goal of uncovering problems that can be fixed prior to launch. The Think Aloud protocol is a method in which users describe their thought processes as they make their way through a Web site. Other methods include contextual inquiry (observation and testing), interviews, journals, various forms of inspection, and performance measurement.

The major criteria are users' success in finding information, including accuracy and speed; related criteria are likability, learning, and retention. For example, in one small study, adults with low literacy were able to learn Web navigation skills easily and use interactive features such as active graphics and pull-down menus when the instructions were simple, direct, and noticeable (Zarcadoolas et al., 2002).

In an effort to identify the types of user-centric strategies currently in use by e-health developers in the field, project staff interviewed 54 developers and other experts about 40 e-health tools designed wholly or partly for diverse users (see Appendix 1). Each of the tools proved to be distinctive in the way it combines functions and features to serve intended users. The analysis of this set of tools suggests the number of user variables that can be considered and the many ways developers think about enhancing relevance and engagement. These developers report that they often consider literacy levels relevant to the use of e-health tools, although the literature review in the next chapter indicates that few studies have systematically included persons with limited literacy skills, designed tools as health literacy interventions, or assessed health literacy as part of the evaluation of the tool.

The scan of 40 e-health tools indicates that developers employ a variety of strategies to enhance the connection between the tools and their intended users. The main strategy appears to be one of targeting or segmentation. The findings align with the observations made in the IOM report, *Speaking of Health: Assessing Health Communication Strategies for Diverse Populations,* about the adaptation of health communication for diverse audiences (2002):

- Some tools are developed for narrowly defined audiences (e.g., people over age 65 with chronic obstructive pulmonary disease; binge-drinking college students). Some developers have an array of such specialized tools or modules.
- Some tools are developed for a broad cross-section of users, but adapted to serve different audience segments (e.g., a Spanish-language version, a module for pregnant women, a chat room for caregivers). The broad cross-section may exist because the tool is available to all comers (e.g., through a public Internet site) or because it is distributed to a restricted but diverse constituency (e.g., employees of a distributor, health plan enrollees).
- Some tools are developed for a broad (and presumably heterogeneous) user group in a way that focuses on what all users have in common.

Often, tools are designed for large population segments based on public health priorities, such as kids with diabetes or adult smokers who are trying to quit. Several developers mentioned the economic impracticality of designing highly segmented or individually tailored tools. Many tools, such as public Web sites, serve anyone who finds the site on the Internet. Others may serve anyone in a more restricted but still heterogeneous group, such as members of a particular health plan or employees of a large organization. Targeting is often based on one or two dominant factors, such as shared health issues, gender, or age. Health condition, risk behavior, and age were the most popular factors for identifying intended users of e-health tools. Some developers stated that the most important characteristic in targeting was the shared health issue, such as people with cancer and their caregivers, rather than demographic factors. The implication is that shared health experience is the basis for coming together via technology. For the majority of the 40 tools, medical conditions (e.g., diabetes) or health-risk behaviors (e.g., smoking) define the audience.

In all, 19 of the 40 tools in the scan were described as having one or more special features for one or more diverse groups. Most consider multiple audience characteristics. The bases for audience segmentation among the tools (listed in order of frequency) are age, language, race/ethnicity, gender, income, geographic location, and disability or sensory impairment. The segments targeted by these tools include:

- Hispanics/Latinos
- Other non-English speakers
- African Americans
- Recent immigrants (e.g., Vietnamese, Caribbean)
- Women
- Teenagers
- Young children
- Elders
- People with low income
- Rural dwellers
- Inner-city dwellers

Added to these variations, several e-health tools have versions for intermediaries or adjunct users such as childcare providers, teachers, parents, school friends, and public health workers. The large group of healthcare tools (i.e., tools made available by healthcare providers or organizations for use by their consumers/patients) are also used by staff members of the healthcare organization, such as nurses, administrative staff, and personal physicians, and these are distinct user groups from the perspective of tool development and evaluation.

The interviews offer examples of developers who adapted a single basic program with multiple subprograms based on factors such as gender, age, or severity of disease. One company has 22 versions of its basic program.  This finding suggests that the often-discussed potential of technology to create customized versions of generic interventions is starting to be realized in the marketplace through a variety of approaches.

## SUMMARY

This chapter identifies several concepts, factors, and strategies that can be used to design e-health tools for diverse users.  The concepts of health literacy and meaningful access highlight the importance of ensuring physical access to information and technology and designing useful, understandable content.  The IOM has already called for greater attention to communication factors in the design of health information, messages, and e-health tools.  This chapter elaborates on many of the critical factors for user-centric design. If the vision of e-health tools for all is to be realized, these factors, along with others that have yet to be fully articulated, will require further research and integration into tool design and development.  A scan of the current field of e-health tools indicates that developers are beginning to address issues of diversity, but do not yet have strategies and approaches that go much beyond traditional public health targeting based on demographic characteristics. Developers will need to engage consumers more fully in the research and design process and probe those factors that shape attitudes, beliefs, values, expectations, and experiences in relation to health and technology.

# CHAPTER 3. ASSESSING THE EVIDENCE FOR E-HEALTH TOOLS FOR DIVERSE USERS

## INTRODUCTION

This chapter summarizes and analyzes recent research literature on e-health tools to clarify what about e-health tools for diverse users is working well and where more and different research is needed. Critics argue that over-reliance on e-health tools can increase disparities rather than reduce or eliminate them; therefore, it is vital to identify when e-health tools can help to narrow gaps. The Institute of Medicine (IOM) report, *Speaking of Health*, proposes that several factors are relevant for assessing e-health for diverse populations: access, availability, appropriateness, acceptability, and applicability of content (2002). This chapter uses these concepts, referred to as the "Five A's," to organize key research findings and discuss their implications for tool design, use, dissemination, and impact. The review suggests that design and dissemination factors are closely connected to and likely to affect the impact of the tools according to a variety of outcome measures.

Previous reviews also have looked at the evidence base for e-health but have not focused as closely on design, use, and dissemination issues as the present review (Eng, 2001; IOM, 2002; Neuhauser and Kreps, 2003; HHS, 1999). These other reviews point not only to the great promise of e-health tools, but also to the need to moderate enthusiasm by recognizing factors that can limit the tools' potential. Numerous individual examples of research-based tools usually produce the desired effects. To date, however, no systematic body of knowledge or theoretical frameworks explain what processes or contextual factors produce and mediate these effects or what the effects would be for different kinds of e-health tools used by different audiences (Neuhauser and Kreps, 2003). Given that some population groups experience a disproportionate amount of disease and overall poor health, it is critical to use the research enterprise to understand if and how e-health tools might be designed and deployed to reduce rather than exacerbate disparities and improve individual and population health.

## METHODOLOGY AND RATIONALE FOR REVIEW

This review selected research studies using experimental design, as well as relevant review articles, that either were meta-analyses or summaries of experimentally based research studies. After the initial round of article selection, the inclusion criteria were made less stringent to increase the breadth of coverage in certain areas. For example, no randomized controlled trials were found for healthcare tools because they are relatively new in the e-health arena. Therefore, studies were included that surveyed user satisfaction and ease of use to provide some insight into these tools. Similarly, in the area of online communities and health information, studies using content analysis provided important findings relative to the potential utility of these tools for different subpopulations; these were also included. Only studies published in peer-reviewed journals were considered. The intent was to identify those studies that used scientific methods and had already been reviewed by the field and found to be significant enough for publication.

Although this approach differs from the most rigorous evidence reviews, such as those conducted by the Cochran Collaboration or sponsored by the Agency for Healthcare Research and Quality, the purpose of the present review is not to differentiate research based on methodological rigor. The intent is to highlight the presence or absence of solid research on key elements affecting e-health use and dissemination. The recent Cochrane Collaboration review, "Interactive Health Communication Applications for People With Chronic Diseases," should be consulted for an example of a rigorous review of the science and conclusions about the effects of e-health tools on persons with chronic diseases (Murray, Burns, See Tai, et al., 2006).

The literature search used the overarching purpose categories to identify studies for inclusion: health information, behavior change/prevention, online communities, healthcare tools, decision support tools, disease management, and health self-management. Research studies for these categories were identified through the use of the following databases: PubMed, Medscape, Medline, PsycINFO, CINAHL, and the Social Sciences Citation Index. The searches covered the time period from January 1999 to September 2004 to identify recent literature. The CRISP (Computer Retrieval of Information on Scientific Projects) database maintained by the National Institutes of Health and covering federally funded biomedical research projects was searched twice approximately 6 months apart in 2004 to identify new research either just being concluded or in progress; the same search terms were used as above. Review of the reference lists and suggestions from an expert panel and expert interviews also identified articles.

Critical information was extracted from each article and summarized into a matrix table. The matrix, presented in Appendix 3, contains data on the study's author, research design, sample, health topic area, locus of use, technology, tool description, study overview, measures, and outcomes. The table is subdivided by study design. The first section includes the studies using randomized controlled designs. The table then moves through quasi-experimental designs, single-group studies, and content analyses. Within each research design subsection, studies are arranged alphabetically by author. Each study has been assigned a unique identifying number to allow easy location of that study in the table. Each citation in this chapter includes a table reference number (TR#). To return to the text from the table, the chapter section in which the study is cited is indicated in brackets after the citation in the table.

## OVERVIEW OF E-HEALTH TOOLS IN STUDIES REVIEWED

Most of the e-health tools in the studies reviewed below are multicomponent interventions designed to impact many aspects of personal health self-management, including prevention, behavior change, decisionmaking, and chronic disease management (see Chapter 1). This review found that although e-health tools have been developed for a wide variety of health topics and purposes, some topics and purposes appear to have greater representation in the research literature. Areas with the largest numbers of tools are nutrition education, weight management, tobacco cessation, and cancer and diabetes prevention and management. Although most of the tools in these studies are designed for adults, some target children and adolescents. Some tools, such as those for behavior change, are grounded in a theoretical framework. Others, such as healthcare tools, are emerging in response to market and policy demands and do not yet have much of a scientific basis to suggest that they will have their intended effect.

Each tool contains health information specific to its intended purpose. This information can be general, targeted to a specific user group, or tailored to an individual user. In addition to information, other features might include interactive games and simulations, video clips, chat rooms, message boards, e-mail to and from healthcare providers, self-assessments, decisionmaking tools, disease management tools, and links to other sites. Tools designed for a similar purpose do not always contain the same components.

Several studies in the review do address the effectiveness of specific components of the computer-based intervention (Baranowski, Baranowski, Cullen, et al., 2003, TR#39; Feil, Noel, Lichtenstein, et al., 2003, TR#10; Napolitano, Fotheringham, Tate, et al., 2003, TR#23; Neighbors, Larimer, and Lewis, 2004, TR#24; Tate, Wing, and Winett, 2001, TR#34). Tate and colleagues used two different e-mail approaches in their study (Tate, Jackvony, and Wing, 2003, TR#33). Both the control group and the intervention group received access to a weight-loss Web site and weekly e-mail reminders to submit their weight; the intervention group also received individual e-counseling from a weight-loss counselor. The researchers found that, compared to the control group without the individualized counseling, the intervention group doubled the percentage of initial body weight lost.

Neighbors and colleagues studied the unique impact of personalized normative feedback alone on drinking behavior in college students and found changes in misperceptions about drinking norms and on drinking behaviors (2004, TR#24). Studies from the D-Net (diabetes) projects indicated that participants using interventions with a support component improved in perceptions of support and actually had higher login rates than the other intervention groups and the controls (Barrera, Glasgow, McKay, et al., 2002, TR#2; Glasgow, Boles, McKay, et al., 2003, TR#13). Studies of CHESS (Comprehensive Health Enhancement Support System), an Internet-based program to help patients cope with cancer and other diseases, have found that use of the component parts of the system vary by a number of demographic factors, including race and income (Gustafson, Hawkins, Pingree, et al., 2001, TR#15; McTavish, Pingree, Hawkins, et al., 2003, TR#88). These types of studies are an important beginning to help clarify what about e-health tools for diverse user groups is working and what is not.

The majority of the tools reported in the research studies were Internet-based interventions that could be accessed from personal computers. Some studies used CD-ROMs to deliver the intervention. Other delivery mechanisms used in these studies included a telephone-linked communications system (Delichatsios, Friedman, Glanz, et al., 2001, TR#9; Pinto, Friedman, Marcus, et al., 2002; TR#27), videophones (Ryan, Kobb, and Hilsen, 2003, TR#73), computers in freestanding kiosks in community settings (Anderson, Winett, Wojcik, et al., 2001, TR#1; Radvan, Wiggers, and Hazell, 2004, TR#70; Valdez, Banerjee, Ackerson, et al., 2002, TR#35), a fingerprint reader (Sciamanna and Clark, 2003, TR#31), and home telehealth units (Finkelstein, O'Connor, and Friedman, 2001, TR#11; Kaufman, Starren, Patel, et al., 2003, TR#63; Ryan et al., 2003, TR#73).

In their reports of findings, researchers do not often discuss their rationale for choosing a specific delivery method. The intended locus of use and the amount of graphics are current factors that appear to influence the decision. For example, Napolitano et al. (2003, TR#23) and Lenert and Cher (1999, TR#65) report that they delivered their interventions via the Internet to reach a potentially wide audience of users who could access the intervention from any location. Proudfoot, Goldberg, Mann, et al. used a CD-ROM-based program with video vignettes, which was designed for delivery in a clinical setting (2003, TR#28). Because it is possible to convert content on compact discs (CDs) for use on the Internet and vice versa, the distinction between formats will likely become less relevant. At the present time, when graphics-heavy CDs are moved onto the Internet, there may be lengthy download times that can affect usability and satisfaction, particularly for those using older computers or slow Internet connections (Baranowski et al., 2003, TR#39). If broadband costs decline and more users opt for high-speed access, connection speed may become less of a problem, but not necessarily, given the size of the access gaps described in Chapter 2.

## SYNTHESIS OF FINDINGS FROM RESEARCH STUDIES OF E-HEALTH TOOLS

### *Access*

Issues of access underlie all studies of consumer e-health tools. This brief section focuses on the impact of disparities in access on the validity of findings reported in the literature. (See Chapter 2 for a general discussion of access issues.) The most important issue relates to the external validity of the research. Findings from this review indicate that many studies included only participants who have computers, thereby excluding those who lack computers or Internet access. A few studies recruited participants directly from Internet Web sites, making it less likely that people without regular access would be considered for the sample. The access criterion for study participation affects the generalizability of the findings for other population groups or the population at large. Because people without computers also tend to have less education, lower incomes, and poorer health, the bias in the current literature must be recognized, and the need for ongoing and future research to include diverse populations is critical.

Access for all population groups is an issue. A few studies, particularly in the area of online communities, have provided participants with computers and expected no computer experience from their participants (Gustafson et al., 2001, TR#15; McTavish et al., 2003, TR#88). These studies are encouraging in that the researchers found that user technology support was not difficult and, ultimately, users were able to use the technology to give and receive support in the online communities. Providing computers for public use can be another avenue for increasing access; however, Radvan et al. found that one reason people did not use a community-placed computer-kiosk for health information was that they did not feel comfortable using the kiosk in public (2004, TR#70).

In a study of older adults, Kaufman et al. found that use of the computer and mouse was very difficult for elderly participants with diabetes who had limited computer experience (2003, TR#63). For this age group, more attention may need to be paid to choosing technology that is suitable to the users' needs. For example, Ryan et al. in the Community Care Coordination Service of the U.S. Department of Veterans Affairs (VA) used a unique approach in which they matched technology to users based on their clinical need and ability, rather than on the availability of a specific kind of technology (2003, TR#73). Their matching process was based on the patient's education, vision, manual dexterity, willingness to use technology, and adherence to medical regimen. Using this approach, they were able to demonstrate improved clinical outcomes in a group of veterans with chronic illnesses.

Davis found that only 19 percent of 500 Web sites representing common illnesses or conditions were accessible for users with visual impairments who used automated screen readers (2002, TR#54). He also notes that almost 65 percent of the Web sites that failed the accessibility test had just a single type of fixable problem. Davis further points out that the best way to make sure a Web site is accessible is to do so from the beginning by following established guidelines, such as those described in Chapter 2 and Appendix 1.

In sum, there appears to be a bias in the literature toward studying those persons who have easy Internet access, can use readily available technologies without adaptation, and do not need much if any technical support. Identifying ways to include currently excluded or understudied groups in future research is critical to creating an evidence base of results that can be generalized as well as specified for select user groups.

### *Availability*

In addition to technology access, people must also have available the information and tools they want and need—that is, meaningful access. Because the Internet seems to be an "always on," universally available channel, there is often the assumption that posting something on the Internet automatically increases information availability. Developing a Web site that contains relevant information is not enough, however, if people cannot locate the site. The studies discussed below suggest that research on information-seeking behaviors is still needed to understand how well different groups can locate health information and tools. (See Chapter 2 for additional information on health information-seeking issues.)

One approach to assessing availability is to go directly to the target audience to conduct a needs assessment. For example, Rozmovits and Ziebland conducted focus groups and interviews with people who had breast or prostate cancer (2004, TR#72). They found that cancer patients had information needs that changed during the course of their illness, and they were not always able to find the information they wanted. Similarly, Goldsmith, Silverman, and Safran found through formative research that parents of children with cancer reported a primary need for help with medication management (2002, TR#60).

Understanding the strategies that people use to locate information is key. Eysenbach and Kohler observed study participants as they tried to locate answers to specific researcher-generated health questions using the Internet (2002, TR#58). They found that although all 16 participants used search engines as starting points and somewhat suboptimal search strategies, they were able to find answers to the questions. However, the researchers did not provide an analysis of the accuracy of the answers or ascertain whether the participants were satisfied with the information they found.

The Pew Internet & American Life Project's 2005 report on search engine use found that 84 percent of Internet users have used search engines, 92 percent of those who use search engines are confident about their searching ability, and 87 percent report successful search experiences most of the time (Fallows, 2005, TR#59). Some user groups, however, have special challenges related to information-seeking. Zarcadoolas, Blanco, Boyer, et al. examined the navigation skills of adults with low literacy and identified several factors that affect availability for this group (2002, TR#81). These include spelling problems that interfere with searching, difficulty entering Web addresses, and difficulty using navigational tools such as graphic links, back arrows, and scrolling.

### *Appropriateness*

Users can have access to technology and the skills to locate information and tools, but still encounter issues related to appropriateness. Appropriateness refers to the fit between the user and the tool. In an attempt to assess appropriateness, researchers have conducted studies on cultural relevance, users' perceptions of the credibility of content, content analyses focused on information quality and readability, and the use of tailoring.

### *Cultural Relevance*

Few of the reviewed studies specifically examined cultural relevance or recruited samples based on racial and ethnic characteristics. Most of the studies did include members of the target audience segmented by age (e.g., college students) or by health or disease status (e.g., women with breast cancer, people at risk for heart disease). Only a few studies conducted research with members of specific ethnic groups to assess cultural relevance (e.g., Campbell, Honess-Morreale, Farrell, et al., 1999, TR#4; Duncan TE, Duncan SC, Beauchamp, et al., 2000, TR#41; Jantz, Anderson, and Gould, 2002, TR#45); Zimmerman, Akerelrea, Buller, et al., 2003, TR#82).

### *Users' Perceptions of the Credibility of Content*

Measuring users' perceptions of the credibility of available information is another means to assess appropriateness. Rozmovits and Ziebland found that study participants were aware of the credibility issues surrounding health information on the Internet, and reported that they often compared information from several different sources before taking it as fact (2004, TR#72). These users preferred information about cancer treatment from noncommercial sites and specifically from institutions with good reputations, such as universities or medical centers.

Eysenbach and Kohler found that users identified many criteria for establishing credibility, such as the source of the information, a professional layout, understandable and professional writing, and citation of scientific evidence (2002, TR#58). Similar to Rozmovits and Ziebland's findings, a few users felt that it is easier to assess information quality on the Internet because they could cross-check information on different sites. When they were actually observed searching for information, none of the participants checked the source of the information and fewer than 25 percent could even tell the broad category of the site they used (e.g., university, Government agency, business).

Barnes, Penrod, and Neiger found a similar disconnect between what users reported as important factors to consider when establishing credibility and actual behavior in assessing Web site quality (2003, TR#46). Walther, Wang, and Loh found an interaction effect of advertisements on user perception of credibility (2004, TR#36). The presence of advertisements on sites with .org domains made the site appear less credible than ads on sites with .com or .edu domains.

Physicians or other healthcare providers could serve as intermediaries to direct patients to appropriate Internet content. The study by D'Alessandro, Kreiter, Kinzer, et al. had physicians provide information prescriptions to patients that contained relevant Internet sites for health information (2004, TR#8). One-third of participants used these prescriptions and were then more likely to state that they would use them again and had already recommended them to others.

### *Content Analysis*

Researchers also assess appropriateness, particularly of publicly available Web sites, by conducting content analyses of the information and performing readability analyses. The overall goal is to measure information quality. Inconsistent findings are reported related to Web site quality. For example, a study by Madan, Frantzides, and Pesce (2003, TR#87) on laparoscopic bariatric surgery and a study by Fahey and Weinberg (2003, TR#85) on LASIK (laser-assisted *in situ* keratomileusis) eye surgery found that the information on the Web in both of these areas was poor and unreliable. One study on diabetes sites found that information quality varied widely (Seidman, Steinwachs, and Rubin, 2003, TR#91). Oermann, Lowery, and Thornley reported that better quality content was found on Web sites sponsored by a university, professional organization, medical center, or Government agency (2003, TR#90). Only the study by Cheh, Ribisl, Wildenmuth, et al. on smoking cessation Web sites found that a majority of the information was accurate (2003, TR#83).

Evers, Prochaska, Prochaska, et al. examined the quality of Internet programs designed to help users change behavior in seven key areas: tobacco use, physical activity, alcohol, diet, diabetes, depression, and pediatric asthma (2003, TR#84). Of the 273 sites examined, only 42 (15 percent) met four of the five minimum criteria determined to have the potential to change behavior. These 42 sites then underwent a full review. All included self-assessments and some form of contact. Only 12 percent included individually tailored feedback, and none included information about evaluation for effectiveness, which was a key recommendation of the 1999 Science Panel on Interactive Communication and Health.

Content readability is usually assessed using readability formulas that provide grade-level assessments. Birru, Monaco, Lonelyss, et al. (2004, TR#48), Kusec, Brborovic, and Schillinger (2003, TR#64), and Oermann et al. (2003, TR#90) found that the average reading levels of the sites they examined was at a 10th-grade level. Birru et al. found some methodological difficulties assessing respondents' comprehension of information on the Internet (2004, TR#48). For example, some respondents could correctly answer interviewers' questions on the content by reciting directly from the Web site. However, when prompted, respondents could not put the answers in their own words. This finding is not surprising because readability analyses do not provide much insight into users' understanding of the content and their capacity to apply the information to specific circumstances. (See Chapter 2 for additional discussion of health literacy issues.)

Eysenbach and Kohler conducted a systematic review of studies that assessed the quality of health information on the Internet (2002, TR#58). Differences in study methodology and quality criteria were used in the reviewed studies, a fact that could explain differences in study results and conclusions. For example, they found that many studies assessed completeness of information; however, this approach generally did not take into account the context or stated purpose of the site or links provided to additional information. They point out that the Internet is not the only type of media delivering information of inconsistent quality, and thus must be considered against the "background of imperfect consumer health information in other media" (p. 2697). One strategy they recommend includes improving the user's ability to locate credible sites and to filter out inadequate ones.

### *Tailoring*

As Chapter 2 indicates, tailoring is thought to be one of the most promising methods to improve the appropriateness of content for users because tailoring simulates an individualized assessment and response. Several tools in the behavior change area evaluated tailored information and feedback using randomized controlled trials (Bernhardt, 2001, TR#3; Campbell et al., 1999, TR#4; Oenema and Brug, 2003, TR#25; Oenema et al., 2001, TR#26). All these trials involved tools tailored to the user's stage of readiness to change. Other tailoring variables included knowledge, dietary intake and habits, awareness of dietary intake as compared with published guidelines, and perceived overweight. These studies all showed positive effects for the tailored information as compared to the control conditions.

In general, the study findings that address appropriateness indicate that users may find it difficult to connect with tools that fit their interests and needs. The success of tailoring suggests the need for much greater attention to the design and testing of elements that make tools a better fit in terms of cultural relevance, consistency, comprehensiveness, and understandability for diverse users.

## *Acceptability*

Acceptability refers to whether people find the tools satisfactory. Satisfaction is typically one criterion that is applied to the evaluation of commercial tools. The fact that millions of people are actively seeking health information online and the phenomenal increase in Internet use speak to a high initial level of acceptability. Researchers and tool developers have focused on usability studies to gauge and improve acceptability, recognizing it as a necessary condition for the ultimate success of e-health tools. Examining use over time can provide an additional measure of acceptability in that it makes it possible to gauge ongoing satisfaction with or usability of programs based on whether people continue to use them.

### *Ease of Use*

Studies of e-health tools designed for a variety of purposes generally found that users report they are easy to use, although some studies found that this was not always the case. Block, Miller, Harnack, et al. reported that 97 percent of users found a nutrition education program easy to use (2000, TR#49). Feil et al. reported that 63 percent of users rated their smoking cessation Web site "easy" or "very easy" to use (2003, TR#10). Some users commented that the smoking cessation site used in the study by Lenert and Cher was complex and difficult to navigate (1999, TR#65). Oenema et al. found that those who had less familiarity with computers also found their tailored program more difficult to use (2001, TR#26).

People using e-health tools designed to allow access to medical records and/or to provide a means to communicate electronically with their healthcare providers were able to use these tools. Participants were able to master the complex login procedures required for privacy and to use the systems effectively; however, these users tended to be more educated, have personal computers, and be covered by a private health insurer (Cimino, Li, Mendonca, et al., 2000, TR#51; Hassol, Walker, Kidder, et al., 2004, TR#62; Masys, Baker, Butros, et al., 2002, TR#68). Sciamanna and Clark examined the acceptability of a fingerprint reader as an alternative means to authenticate users in a medical clinic, thus eliminating the need for complex login procedures (2003, TR#31). Those who used the fingerprint reader did not appear to under-report information and had fewer concerns about the reader than did those who did not use the reader.

More difficulties were found when the study populations were chronically ill, elderly patients with little or no computer experience. Caregivers of patients with dementia generally found the telephone-linked support system easy to use, but a small percentage of users had difficulty reading the screen or hearing the messages (Czaja and Rubert, 2002, TR#53). Kaufman et al. found that the use of the computer mouse for a diabetes home telemedicine system was exceedingly difficult for some of their elderly participants (2003, TR#63). Furthermore, all of the novice users experienced difficulty in developing a coherent mental model of the system and were frustrated by their inability to navigate screen transitions.

McKay, Glasglow, Feil, et al. found that the diabetes self-management component of their Web site, which guided participants in tracking blood glucose levels throughout the day, was not used often (2002, TR#21). They concluded that the tool might have been too complex for participants to use regularly. The VA program by Ryan et al. that matched technology to user ability found that patients were highly satisfied with the technology and 95 percent of users rated their technology "easy to use," indicating that with careful selection of technology, these types of problems can be solved (2003, TR#73).

### *Satisfaction*

Self-reported satisfaction levels have been high for tools across a wide range of purposes. People showed high levels of receptivity to e-health tools to aid decisionmaking for the treatment of benign prostatic hypertrophy (Lenert and Cher, 1999, TR#65), genetic testing for breast cancer (Green, Peterson, Baker, et al., 2004, TR#14), and contraceptive use (Chewning, Mosena, Wilson, et al., 1999, TR#6).

Healthcare tool users were also very satisfied. Liederman and Morefield found that 78 percent of their sample of RelayHealth users rated Web messaging "better" or "much better" than calling their doctor, and they reported that electronic communication improved access to their practitioner (2003, TR#67). Tang, Black, Buchanan, et al. found that patients using the PAMFOnline system (Palo Alto Medical Foundation) rated online messaging highly, even though a subscription fee was associated with this function (2003, TR#76). The researchers also found that the majority of users identified getting lab results as the most important benefit of having access to their medical records (2003, TR#76). Hassol et al. surveyed members of the Geisinger Health System who were "early adopters" of the MyChart application (2004, TR#62). They reported that patients saw online communication as especially useful for general medical questions or prescription renewals.

Constraints of the technology at times affected satisfaction. Liederman and Morefield found that satisfaction with Web-based messaging correlated with response time (2003, TR#67). Those who felt they received a timely response to their messages were "very satisfied" (74 percent) with the system; likewise, those who reported a slow response from the clinic were dissatisfied (6 percent). Patients used the telephone when the electronic system was not in place yet, when they wanted quicker responses, or when it was easier to explain the problem orally than in writing.

Others liked using e-health tools as an adjunct to medical care in physicians' offices or clinics. Wilkie, Huang, Berry, et al. found that patients liked using computerized assessments to help assess their levels of pain and fatigue (2001, TR#78; Wilkie, Judge, Berry, et al., 2003, TR#79). Patients reported that the tool gave them the ability to describe their pain more specifically, enabling better discussions with their physicians.

In addition, surveys conducted with people who use online health communities show that they identify many advantages of online community use. For example, groups are available 24 hours a day, 7 days a week (Han and Belcher, 2001, TR#61; Shaw, McTavish, Hawkins, et al., 2000, TR#74). They do not have to be concerned about their appearance (Shaw et al., 2000, TR#74) or other issues related to attending face-to-face groups (Shaw et al., 2000, TR#74; Czaja and Rubert, 2002, TR#53). They perceive equalized participation among group members due to anonymity (Colvin, Chenoweth, Bold, et al., 2004, TR#52) and the lack of social context cues, such as dress or appearance (Shaw et al., 2000, TR#74).

Other advantages are that people also can exchange information (Finn, 1999, TR#86; Mendelson, 2003, TR#89); share personal feelings (Shaw et al., 2000, TR#74), support, and coping strategies (Mendelson, 2003, TR#89); feel less alone (Reeves, 2000, TR#71; Shaw et al., 2000, TR#74) and less depressed (Lieberman, Golant, Giese-Davis, et al., 2003, TR#66); help others (Reeves, 2000, TR#71); and gain feelings of empowerment (Finn, 1999, TR#86; Reeves, 2000, TR#71). Preece, Nennecke, and Andrews found that people who posted to online communities had a greater sense of belonging and satisfaction than people who visited the communities but did not post (2004, TR#69).

Online community users do report some disadvantages, such as the time commitment needed to review large volumes of postings (Han and Belcher, 2001, TR#61; Shaw et al., 2000, TR#74), a lack of physical contact or proximity to other group members (Colvin et al., 2004, TR#52; Han and Belcher, 2001, TR#61), dealing with "noise" or off-topic postings, and the generation of negative emotions because they were exposed to others' losses or problems (Han and Belcher, 2001, TR#61). Technical problems, such as difficulty with posting, can also be a disadvantage (Colvin et al., 2004, TR#52; Lieberman et al., 2003, TR#66).

Users were generally satisfied with tools designed to help them adopt healthier behaviors. For example, Lenert and Cher reported that 94 percent of the users of their smoking cessation site felt the site had helped their quit effort (1999, TR#65). In a tailored nutrition program, 79 percent of users reported that the program was helpful and most would use it again (Campbell et al., 1999, TR#4). About 90 percent of users of a nutrition education program reported that they had learned something new and would recommend the program to others (Block et al., 2000, TR#49). In a study by Woodruff, Edward, Conway, et al., 95 percent of teens would recommend the smoking cessation site to other teen smokers (2001, TR#80). McKay, King, Eakin, et al. found that the users in the intervention group were more satisfied with an intervention designed to increase levels of physical activity than were users in the computer-based information-only control group (2001, TR#22).

Only one reviewed study reported participants' negative feelings about an Internet group (Harvey-Berino, Pintauro, and Gold, et al., 2002, TR#16). The researchers found that people preferred in-person groups for weight-loss maintenance rather than Internet groups; however, all of these participants had previously attended in-person weight-loss groups.

In contrast, McKay et al. found that nearly 60 percent of patients with diabetes in primary care practices were willing to participate in a computer-based diabetes management intervention (2002, TR#21). They believe this reflects a substantially higher percentage than would be willing and able to attend traditional educational programs.

Most surveys of satisfaction examine the tools as a whole. The study by Weis, Stamm, Smith, et al. of users of a site for persons with multiple sclerosis examined satisfaction with components of the site (2003, TR#77). They found that, in general, users preferred the information functions to the support functions of this site. Users who used both functions gave the site the highest overall ratings. Women rated the information function higher than did men; adults with children rated all functions higher than did those without children; and younger users rated the support functions higher than older users did. Escoffery, McCormick, Bateman, et al. also found that participants who used their smoking cessation site preferred the informational components to the "ask the expert" and message board features (2004, TR#57).

### *Usage Over Time*

Studies that monitored login rates showed that logins were most frequent in the beginning of the intervention. They also found that participants used the programs less frequently and/or did not complete all modules as time passed (Clarke, Reid, Eubanks, et al., 2002, TR#7; Glasgow et al., 2003, TR#13; Irvine, Ary, Grove, et al., 2004, TR#17; McKay et al., 2001, TR#22; McKay et al., 2002, TR#21; Pinto et al., 2002, TR#27; Tate et al., 2001, TR#34; Tate et al., 2003, TR#33). Four studies found evidence of a dose-response relationship, with increased use leading to better outcomes (Celio, Winzelberg, Wilfley, et al., 2000, TR#5; Delichatsios et al., 2001, TR#9; Frenn, Malin, Bansal, et al., 2003, TR#42; McKay et al., 2001, TR#22). However, Pinto et al. did not find this effect (2002, TR#27).

Although the decline in usage may indicate some level of dissatisfaction, users in the intervention groups had higher login rates than persons in the computer-based control groups throughout the duration of the studies (McKay et al., 2001, TR#22; Tate et al., 2001, TR#34; Tate et al., 2003, TR#33). Further, the studies by Glasgow et al. (2003, TR#13) and McKay et al. (2002, TR#21) used multiple intervention groups. Similarly, they found that not only did the intervention groups use the program more than the control groups, but also the intervention groups that included a social support component had more logins than the other intervention groups.

There is almost no information on how this decrease in utilization compares to what might occur in traditional face-to-face interventions. The only exception is that McKay et al. reported that their dropout rate of 16 percent was "somewhat" higher than a similar intervention conducted in person (2002, TR#21).

Researchers identify several factors with the sites and users that might have caused attrition. Participants in a study by Napolitano et al. reported that because the Web site did not change over time, they did not need to return (2003, TR#23). Lenert and Cher reported that their site was too complex, relied too heavily on text, and required too much self-direction to locate pertinent information (1999, TR#65). They further hypothesized that people who enroll in an Internet-based program may not be as committed as those who enroll in traditional face-to-face interventions. McKay et al. thought that the Internet might be more conducive to surfing behavior and less to use of a single site (2001, TR#22). Developing Web sites that keep users coming back is a challenge (Glasgow et al., 2003, TR#13), and more research is needed to determine how to stimulate ongoing use (McKay et al., 2001, TR#22).

Other studies have identified some strategies that can be used to attract and keep users. Bowen, Ludwig, Bush, et al. found that the use of e-mail cues increased the number of women who logged in to a breast cancer information site (2003, TR#50). They found that the most common reason for nonusage was finding the time to get online. Feil et al. found no difference in attrition between groups receiving a $10 incentive and groups receiving a $20 incentive, and no difference in response to follow-up using either e-mail or regular postal service reminders (2003, TR#10). Although large numbers of people search the Internet and see many advantages to the Internet as a channel for health information, research has yet to focus on what will hold the interest of diverse sets of users and motivate them to return to a tool again and again.

## Applicability

Applicability is related to utility and outcomes. Because most research studies treat e-health tools as an intervention, studies typically are designed to measure the impact of the tools on a wide range of outcomes, ranging from changes in knowledge to health status. Many different types of tools were found to produce different types of positive outcomes. The findings summarized here are from studies using control group comparisons, either in randomized clinical trials or quasi-experimental designs. Only one study involved the evaluation of a commercial Web site (Womble, Wadden, McGuckin, et al., 2004, TR#38).

### Knowledge and Information Needs

e-Health tools have been found to increase knowledge in a wide range of areas, including:

- Nutrition knowledge in low-income African American women (Campbell et al., 1999, TR#4) and low-income Hispanic women (Jantz et al., 2002, TR#45)
- Skin cancer causes and prevention in children (Hornung, Lennon, Garrett, et al., 2000, TR#43)
- Breast cancer in low-income Hispanic women (Valdez et al., 2002, TR#35; Green et al., 2004, TR#14)
- Alcohol use and effects in college students (Reis, Riley, Lokman, et al., 2000, TR#29)
- HIV prevention in adolescent girls (DiNoia, Schinke, Rena, et al., 2004, TR#40)
- Oral contraceptives in adolescent girls (Chewning et al., 1999, TR#6)
- Asthma in children (Krishna, Francisco, Balas, et al., 2003, TR#18; Lieberman, 2001, TR#19) and their caregivers (Krishna et al., 2003, TR#18)

Gustafson et al. found that race, education level, and insurance status interacted with use of CHESS (2001, TR#15). This system helped women of color, more than Caucasian women, to overcome the perception of unmet information needs and increase their perception of participation in their own health care. Education levels and health insurance status were found to interact in the same way as race and ethnicity, with women with less education and less health insurance receiving more benefit. McTavish et al. found that women of color used a CHESS discussion group differently than white women in that the communications by women of color focused more specifically on information about breast cancer and its treatment, whereas white women were more likely to discuss daily life or offer mutual support (2003, TR#88).

### Attitudes and Beliefs Theorized to Mediate Behavior Change

Positive changes in attitudes and beliefs were seen in the following areas as a result of interacting with e-health tools:

- Increased self-efficacy for
  - — Improving dietary habits in adults (Anderson et al., 2001, TR#1; Irvine et al., 2004, TR#17)
  - — Protecting self from HIV in college students (DiNoia et al., 2004, TR#40)

  - Refusing marijuana in high school students (Duncan et al., 2000, TR#41)
  - Self-managing asthma in children with asthma (Lieberman, 2001, TR#19)
  - Self-managing diabetes in children (Lieberman, 2001, TR#20)
- Increased intention to
  - Change eating habits in adults (Irvine et al., 2004, TR#17; Oenema and Brug, 2003, TR#25; Oenema, Brug, and Lechner, 2001, TR#26)
  - Refuse marijuana in high school students (Duncan et al., 2000, TR#41)
  - Ask physician about mammograms in Latina women with low incomes and limited education (Valdez et al., 2002, TR#35)
- Affect motivational readiness to change related to
  - Eating behaviors in low-income, primarily African American women (Campbell et al., 1999, TR#4)
  - Physical activity in sedentary adults (Napolitano et al., 2003, TR#23; Pinto et al., 2002, TR#27)
- Affect outcome expectations related to
  - Healthier eating in adults (Anderson et al., 2001, TR#1)
  - Alcohol use in college students (Reis et al., 2000, TR#29)
  - Oral contraceptive use in white and African American, sexually active adolescents (Chewning et al., 1999, TR#6)
- Increased positive attitudes and decreased barriers about skin cancer prevention in elementary school students (Hornung et al., 2000, TR#43) and college students (Bernhardt, 2001, TR#3)
- Increased realistic perceptions about food intake (Oenema and Brug, 2003, TR#25)
- Decreased misperceptions about peer drinking in college students (Neighbors et al., 2004, TR#24)
- Decreased weight and shape concerns in college students (Celio et al., 2000, TR#5)

### *Social Support*

Two randomized controlled trials measured perceived social support and showed that it can be affected (Barrera et al., 2002, TR#2; Gustafson et al., 2001, TR#15). One of these studies examined a multifunctional program (CHESS), so the relative contribution of the support components cannot be determined (Gustafson et al., 2001, TR#15). Barrera et al. found that those in the support conditions (social support alone and combined social support with coach) increased their perceptions of the availability of social support as compared to the information-only control group or the group that had access to a "personal coach" (2002, TR#2).

### *Decision Support*

Two studies examined decision support tools designed to be used as an adjunct to clinical care. Green et al. studied the effect of using a computer-based decision aid about breast cancer susceptibility and genetic testing (2004, TR#14). Those in the intervention group interacted with the computer and received genetic counseling; the control group received only genetic counseling. After using the computer program, women with a low risk of breast cancer were able to reduce their perceived risk of getting breast cancer and their intention to undergo genetic testing, and this perceived risk was further reduced after the genetic counseling session. At baseline, more than 80 percent of women in both groups indicated their intention to receive genetic testing; at follow-up, only 19 percent had actually undergone testing.

Chewning et al. studied the effect of a computer-based contraceptive decision aid designed to promote effective selection and contraceptive use in sexually active adolescent girls during visits to family planning clinics (1999, TR#6). The decision aid was evaluated in two clinics, one with a primarily Caucasian population (Madison, Wisconsin) and the other with a primarily African American population (Chicago, Illinois). They found that significantly more of those in the intervention group in Chicago followed through with their intention to use oral contraceptives as compared to the Chicago control group, with a similar but statistically nonsignificant trend in Madison.

### *Health Behaviors*

Use of specific e-health tools has been shown to affect health behaviors as follows:

- Improve dietary habits in
  - — Adult supermarket shoppers (Anderson et al., 2001, TR#1)
  - — Adult workers (Irvine et al., 2004, TR#17)
  - — Adults with type 2 diabetes (Glasgow et al., 2003, TR#13; Glasgow and Toobert, 2000, TR#12; McKay et al., 2002, TR#21)
  - — Sedentary adults (Delichatsios et al., 2001, TR#9)
  - — Low-income, primarily African American, women (Campbell et al., 1999, TR#4)
  - — Middle school students (Frenn et al., 2003, TR#42)
  - — Elementary school children (Baranowski et al., 2003, TR#39)
- Increase physical activity in
  - — Sedentary adults (Napolitano et al., 2003, TR#23; Pinto et al., 2002, TR#27)
  - — Adults with type 2 diabetes (McKay et al., 2001, TR#22)
- Reduce drinking in heavy-drinking college students (Neighbors et al., 2004, TR#24)
- Decrease disordered eating behaviors in college students (Celio et al., 2000, TR#5)
- Increase adherence to
  - — Medical protocol in adults with congestive heart failure (Ross, Moore, Earnest, et al., 2004, TR#30)
  - — Asthma action plans (Finkelstein et al., 2001, TR#11)

Two studies compared their findings to objective outcome goals. Although Baranowski et al. (2003, TR#39) and Frenn et al. (2003, TR#42) found that they were able to positively impact the dietary habits of study participants, the improvements were not enough to meet dietary guidelines.

### *Health Outcomes*

Researchers have used a variety of e-health tools to affect health outcomes. The results, which are mixed, are summarized in the following.

**Weight Loss.** Two studies by Tate et al. found that an Internet-based weight-loss program led to significant weight loss in overweight adults (2001, TR#34; 2003, TR#33). Harvey-Berino et al. found no difference in weight loss between those using an online program as compared to those attending an in-person group (2002, TR#16). Womble et al. compared weight loss in overweight women who were randomly assigned to use a commercial dieting site (*eDiets.com*) or a weight-loss manual (2004, TR#38). In the strictest analysis of data, they found that the group using the manual lost significantly more weight than the group using *eDiets.com*.

**Pregnancy.** In a study of contraceptive use, there were no differences between control and intervention groups in the discontinuation of oral contraceptives. There was a statistically nonsignificant trend toward decreased pregnancy in Madison for those who used the computer-based decision aid, but no difference between groups in the Chicago sample (Chewning et al., 1999, TR#6).

**Mental Health and Quality-of-Life Outcomes.** Proudfoot et al. found decreased levels of depression and anxiety in people with those conditions (2003, TR#28). Clarke et al. found no effect of their Internet program on depression; however, process evaluation showed low usage of the program overall (2002, TR#7). Winzelberg et al. found significant changes in measures of depression, stress, and cancer-related trauma in women with breast cancer, but no difference in anxiety or coping for women (2003, TR#37). A possible explanation is that the intervention was not designed to affect these measures directly. Smith and Weinert found no differences between study groups on psychosocial and quality-of-life measures in women with diabetes, although this may be due to a small sample size (2000, TR#32). The participants did report that the project provided a great deal of support and feelings of connectedness. No changes in quality-of-life measures were found in adults with type 2 diabetes (Glasgow and Toobert, 2000, TR#12). Both groups (*eDiets.com* and manual) in the study by Womble et al. showed improvements in quality-of-life measures and less depression during the course of the study, but there were not significant differences between the groups (2004, TR#38).

**Physiological Measures.** Modest changes were found in cholesterol and lipid ratios along with small reductions in glycosylated hemoglobin (HbA1c) levels in adults with type 2 diabetes (Glasgow et al., 2003, TR#13; Glasgow and Toobert, 2000, TR#12), but no change was found in these measures in a study by McKay et al. (2002, TR#21). No difference was found in blood pressure, glucose, lipids, or lipoproteins between groups in the Womble et al. (2004, TR#38) study.

### *Possible Negative Outcomes*

Some researchers have posited possible negative effects, such as increased depression or social withdrawal, from Internet use. Several studies show that those who seek help in online communities may have more serious conditions than those who do not (Beebe, Asche, Harrison, et al., 2004, TR#47; Epstein, Rosenberg, Grant, et al., 2002, TR#55; Erwin, Turk, Heimberg, et al., 2004, TR#56; Houston, Cooper, and Ford, 2002, TR#44). However, these studies were not randomized controlled trials. It is not clear that Internet use is the cause of this greater impairment. It is equally possible that those who need support and lack it in their face-to-face relationships are trying to attain support via the Internet (Beebe et al., 2004, TR#47).

Another area of concern relates to the possibility that patients could become distressed or anxious by something they read as a result of having electronic access to their medical records (Tang et al., 2003, TR#76; Masys et al., 2002, TR#68). Tang et al. used hyperlinking to link medical terms to a dictionary to improve patient understanding, but they did not evaluate the impact of this feature (2003, TR#76). Masys et al. set up safeguards, including a toll-free hotline number, to protect patients; however, they found that this concern was unfounded for this group of participants (2002). Participants using SPPARO (System Providing Patient Access to Records Online), a Web-based online medical record, did not report any negative effects (Ross et al., 2004, TR#30).

## *Cost Savings and Return on Investment*

Although not part of the "Five A's" framework, described at the beginning of this chapter, the effect of e-health tools on costs and return on investment for healthcare organizations, insurers, employers, and the Government is of strong interest in the policy and healthcare communities.

Researchers are beginning to calculate the financial impacts of the use of e-health tools. Krishna et al. provided evidence that using an e-health tool for asthma self-management education is cost-effective (2003, TR#18). This study showed reductions in emergency department visits in the intervention group that translated into a savings of approximately $907.10 per child as compared with a savings of only $291.40 per child for the control group. Other indirect savings were discussed but not calculated. For example, the children in the intervention group used a significantly lower average dose of inhaled corticosteroids by their third clinic visit, thus leading to a reduction in medication expenditures. In addition, they reduced school absences during the study period by an average of 5.4 days per child per school year as compared with 1.6 days for children with asthma in the control group. These indirect savings would be realized by working parents and their employers.

In a randomized clinical trial, 59 children and adolescents, age 8 to 16, improved their self-care and reduced their emergency clinical utilization after playing Packy & Marlon, a health education and disease management video game (Lieberman, 2001, TR#20). They reduced diabetes-related urgent and emergency visits by 77 percent after 6 months of access, compared to no reduction in clinical utilization in a control group of youngsters with diabetes who used an entertainment video game with no health content.

Ross et al. found no difference in hospitalizations or mortality between patients who used SPPARO and those who did not have access (2004, TR#30). Those who used SPPARO did have more emergency department visits; however, these did not temporally relate to use of SPARRO.

e-Health tools can also result in savings by enabling patients to perform monitoring tasks that professionals would do. For example, Finkelstein et al. demonstrated that lung function test results collected during home asthma telemonitoring were comparable to those collected under the supervision of trained professionals (2001, TR#11).

## SUMMARY AND DISCUSSION

This chapter provides a review of recent research pertaining to e-health tools and factors affecting their use by diverse population segments. Overall, the research continues to inspire a sense of promise for these tools as many positive findings have been reported across different categories of tools with a wide variety of components. The lack of diversity in the samples used in these studies, however, makes very clear one of the key messages of this report. The body of knowledge about which groups will engage with and benefit from e-health implementation is thin and must be developed using a model of diversity if the tools are to achieve their potential as public health interventions. This section summarizes the research reviewed in this chapter and examines the limitations and challenges of current research.

### *The Body of Research*

Existing research on e-health tools clusters around two broad areas: (1) evaluation of public domain e-health tools and Internet use, and (2) development and evaluation of specific tools developed and tested in research settings. Research on tools in the public domain includes quality assessments and readability analyses of online content, content analyses of online communities, and surveys and observations about how people use the Internet.

The general public appears satisfied with the information and support online; however, content analyses find that the quality of the information is less than optimal. Furthermore, readability and other access issues may make online use difficult for members of diverse populations. Evaluation of e-health tools can benefit users by improving the quality and effectiveness of the tool, minimizing the chance of harm, promoting innovation in the tools, conserving resources, and allowing users to make informed choices about tools (Eng, Maxfield, Patrick, et al., 1998). Only one study evaluated a widely available commercial e-health tool (*eDiets.com*) in a randomized controlled trial, the results of which were not favorable.

The second broad area of research focuses on the development and evaluation of specific e-health tools. These studies provide information about the usability, efficacy, and effectiveness of the tools. The quantity and quality of the research is uneven across topics and tools. Some areas, such as tools for behavior change, are theory-based and have generated sound research and evaluation to support their use. Many multiple randomized controlled studies across several health topics have found positive outcomes. Other tools, such as healthcare tools, that are emerging in response to market and policy demands do not yet have much of a scientific basis to suggest that they will have their intended effect. Most of the research on these tools is focused on satisfaction and usability.

Unfortunately, many research-based tools are not widely distributed or easily accessed by the general public. It is important to bring evidence-based e-health tools to those who can benefit from them. The reverse is also true. It is just as important to use the findings about what people actually need, desire, and do while online to guide the development of research-based e-health tools. Much work remains to be done to bridge the gaps between these areas. Chapter 4 discusses this topic in greater detail.

### *The Tools*

Although the literature review and the scan of tools in the field identified a large number of tools, there are no standard, accepted definitions for purposes or components of tools for consumers. In general, the tools tend to be multicomponent programs that have been designed for many purposes: to inform, provide support, aid behavior change, assist decisionmaking, help manage disease, and facilitate interaction with the healthcare system. Some research studies clearly describe the tool being studied; others provide only vague descriptions. Some tools with similar stated purposes have notably different components. The wide range of tools reflects the array of burgeoning and exciting possibilities that can be offered through electronic media, but it also makes the comparison of different studies and future replications difficult.

More needs to be known about e-health tools, including the identification of critical components and combinations of components as well as the optimal conditions for use of these tools. Individual studies may answer one or two questions about use, but there is not yet a body of research that indicates who should use these tools, when, where, how frequently, and how intensively. Factors that lead to user adoption and ongoing use as well as factors that lead to attrition also need to be identified.

It is encouraging that many studies have found positive changes in knowledge and intention after just one interaction. Findings on actual behavior change and health outcomes have been less clear. However, many of these studies may not have provided interventions with enough frequency or intensity to bring about desired changes in these areas.

## *Key Findings of the Review by Access, Availability, Appropriateness, Acceptability, and Applicability*

### *Access*

Millions of people are using the Internet for health-related purposes, and estimates can be made about the deployment of e-health tools in large, closed systems, such as the VA's My Health*e*Vet. Beyond this, little is known about actual uptake and use of e-health tools. Few if any data exist on the distribution of e-health tools across the population or within subgroups. Population and subgroup data on level of interest in and attention to these tools also are not available. Large numbers of e-health tools have been developed, but it is not known how many people know about these tools, how many are using these tools, and how many could be influenced to try them. The ability of interested users to locate and access these tools, particularly those with a credible research basis, is also unknown.

### *Availability*

A major issue that emerges from this review is the limited external validity of much of the research, as so many of the studies utilized convenience samples or required computer ownership. This approach has led to a disproportionate amount of information on Caucasian women with higher education. Even when studies reported the demographics of their samples, most did not analyze their findings according to these variables. A few exceptions exist, such as the findings from CHESS, in which women of color, women who were less educated, and women with less health insurance appeared to derive greater benefits from interacting with CHESS (Gustafson et al., 2001, TR#15). Similarly, Oenema and Brug found that respondents with less education seemed to have benefited more from the tailored nutrition feedback than did those with higher education (2003, TR#25). Frenn et al. also found evidence that their intervention had a differential effect based on race and gender of users (2003, TR#42). The lack of diversity in the research samples and evidence of differential effects based on demographics suggest major gaps in our knowledge about how to address issues of access as well as the acceptability and appropriateness of personal e-health tools for diverse segments of the population.

### *Appropriateness*

Some tools have been recently developed that target special populations, and some of these were developed with input from the target audience. These studies show that with careful attention to cultural, literacy, and technological needs, successful tools can be developed for and used within these subpopulations (Campbell et al., 1999, TR#4; Jantz et al., 2002, TR#45). User-centered design and usability research, along with participatory research methods, can be used to bridge the gap between what designers and researchers envision and what the ultimate end users actually find engaging and helpful. It is critical to seek input about the diverse needs of all potential users during tool development and ensure that they are represented in the evaluation studies.

Any review in this area should consider how technology is used in the research projects. The studies that required participants to use their own computers found that the capabilities of users' technology can vary tremendously. At times, researchers have found that participants were not always able to access all parts of the programs being tested. These kinds of studies are important because they help determine the feasibility of delivering e-health tools over the Internet. Other studies had participants interact with an e-health tool in a lab or clinical setting. This allows for potentially greater representation in the study sample, helps minimize potential technical problems, and gives an idea of the efficacy of a tool, that is, its success under very controlled conditions. Information from both of these kinds of studies is important for building the knowledge base for e-health tools.

### *Acceptability*

Findings from the studies in the Acceptability section reveal that people like e-health tools and generally find them easy to use. There does seem to be a decline in usage over time, but the declines were not as steep as those found in the control conditions. It is not known how this decline compares to other intervention formats, such as in-person educational or therapeutic programs. Several researchers have ideas about why dropoffs occur; they posit that sites are too complex or not dynamic enough. Research will need to continue to investigate these factors. A research path would be to examine what personal qualities lead to preferences for online interventions or whether differences exist between those who seek help online and those who seek face-to-face interventions.

### *Applicability*

The studies in this section found many positive findings, but some design issues deserve further mention.

**Measures.** These studies showed a strong reliance on self-reported data to document change. Typically, self-reported data are considered weaker than other types of objectively collected data and subject to bias. Because participants tend to make their responses more socially desirable, the effects may be overstated. Also, many of the studies use questionnaires or adapt existing questionnaires without reporting reliability or validity. This could affect findings in unknown ways. To establish firmly the effectiveness of these tools, researchers must continue to develop and utilize objective, reliable, and valid measures.

From a health literacy perspective, an equally important issue may be the mismatch in understanding between researchers and study participants about what is being measured. The health literacy construct highlights the frequent gap in understanding between health professionals and nonprofessionals. Particularly when the use of technology is involved, attitudes, beliefs, and expectations may play an important role in shaping how users interact with the systems and report data.

**Frequency, Duration, and Intensity.** The studies examined a variety of tools under a variety of conditions. Some studies exposed participants to the intervention for only one short session; others made a Web site available to users over a specified period of time. Because of the differences in the tools, it is difficult to compare the effects of frequency, duration, and intensity across studies. There does appear to be a dose-response relationship in which those participants who showed the greatest use of a tool also showed the greatest benefit. No studies formally manipulated the frequency, duration, or intensity of use.

**Types of Control Groups.** The types of control groups used in these studies varied. Some control groups received no intervention. Others received treatment as usual, which might include in-person contact or informational brochures. It is possible that the positive effects of such comparisons in these studies are due to the use of the computer itself rather than the specific intervention.

Studies are beginning to appear that have control groups using alternative computer-based activities. For example, while the intervention group in the study by Jantz et al. used a program about nutrition, the control group interacted with a program on household budgeting (2002, TR#45). This type of comparison allows researchers to make a stronger case for attributing findings to the computer-based intervention itself rather than the novelty of the channel. Gustafson et al. points out that some of the benefits seen in their study may be due to loaning participants a computer, although they dispute this because their data showed significant actual use of the CHESS program (2001, TR#15). Further evidence is seen in the study by Barrera et al. in which the control group had computer access, but did not show the same benefits as the intervention groups (2002, TR#2).

**Capitalizing on Digital Technology for Research.** Although evaluation of e-health tools shares many similarities with evaluation of other health-related media, some unique opportunities are specific to the use of digital technology. Research is beginning to capitalize on these attributes. For example, several studies used computer-based assessments that can streamline the data collection and entry process. Anecdotal evidence suggests that this approach can be a less threatening way of collecting data from populations with low literacy. Other studies have used online tracking systems that can help determine if participants actually used the programs and in which areas they spent their time. This type of process information can be very important in helping to determine what users find attractive and which program components are effective.

## *Final Thoughts*

The research enterprise will need to be harnessed in a more coordinated and focused manner to ensure access and the availability of appropriate tools for people who want and need them. As noted in Chapter 1, "doing better" in the application of e-health tools to population health improvement means finding the best approaches to create tools that are "participatory, deeply meaningful, empathetic, empowering, interactive, personally relevant, contextually situated, credible, and convenient" (Neuhauser and Kreps, 2003). Meeting these requirements will entail much greater attention to the use of participatory research methods and samples that reflect population diversity than demonstrated in the current body of research.

## ENDNOTE: SEARCH TERMS

The following search terms were used in the search strategy for Chapter 3:

**Health Information:** A preprogrammed PubMed search was conducted under *Healthy People 2010* objective 11-4—Increase the proportion of health-related World Wide Web sites that disclose information that can be used to assess the quality of the site—using the following search terms (internet/standards[majr] AND (web OR website OR websites) AND (quality assurance OR quality control[mesh] OR confidentiality[mesh] OR privacy[mesh] OR ethics[mesh] OR health education/standards[mesh] NOT letter[pt] AND English[1a].

**Behavior Change/Prevention:** (Internet OR computer OR CD-ROM OR interactive multimedia) AND (behavior change OR health promotion OR prevention)

**Online Communities:** (Online OR Internet OR computer-mediated) AND (communities OR chat groups OR chat rooms OR listservs OR discussion groups OR support groups) AND health

**Healthcare Tools:** Personal electronic health record, personal electronic medical record, electronic messaging. Searches also were conducted for research related to specific healthcare tools as identified in the expert interviews.

**Decision Support:** Decision support, decision support tools, decision support AND online, decision aid

**Disease Management:** Disease management, disease management health tools, self-care tools, consumer health management tools

# CHAPTER 4. STRATEGIC FACTORS IN REALIZING THE POTENTIAL OF e-HEALTH

## INTRODUCTION

This chapter looks at the forces that are connecting consumers and e-health tools and creating a dynamic e-health marketplace. It depicts an e-health arena that is evolving in response to cultural and technological trends, market and health system forces, and policy initiatives. It also identifies the limits of the current e-health market to coordinate e-health tool development, evaluation, and dissemination; generate sustainable business models for e-health tools; and provide strong privacy protections and quality assurance to nurture public trust. These activities are generally beyond the market's capacity to address on its own because they require changes and investments for which there is no immediate or direct return on investment for individual stakeholders. Given the public interest in and policy commitment to universal access to broadband technologies and electronic health records noted in Chapter 1, the public sector has the ultimate responsibility for ensuring these limitations are addressed.

Government coordination of efforts to realize the public health potential of e-health tools could be synergistic with existing public-sector programs and could help advance a number of important policy goals, including eliminating health disparities and supporting consumers in taking more responsibility for their health. Government cannot achieve these changes alone, however; it needs to join forces with the many stakeholders profiled in this chapter to design and carry out strategies from which every participant can derive appropriate benefits.

## SIGNS OF DYNAMISM

Consumer e-health is part of the broad cultural shift toward Internet and technology use, such as portable music devices, cell phones, instant messaging, and interactive voice-response systems, as a normal part of everyday life. At the end of 2004, approximately 70 million Americans used the Internet on a typical day for activities as varied as banking, shopping, real estate transactions, research, entertainment, self-expression, and voting; the Internet is "the new normal" (Rainie and Horrigan, 2005).

The same information and communication technologies that enable these other activities offer opportunities in the health arena as well. For example, hardware is becoming smaller, more powerful, cheaper, and more portable. Software is evolving to permit the storage and integration of ever-greater volumes of information. Search engines are proliferating and becoming more robust. Communication technology is enabling greater speed, the use of multimedia, and increasing mobility. All these factors can be conducive to wider dissemination of e-health tools, provided ubiquitous broadband access can be achieved.

There are many signs of the dynamism of the e-health environment, as demonstrated in the following examples.

- Manhattan Research reported in 2002 that the number of e-health consumers was growing at twice the rate of the overall online population (eHealth Institute, 2002, p. 16).
- The National Library of Medicine reported that the number of unique MedlinePlus users grew more than threefold, from 16 million to 52 million, between 2003 and 2004 (B. Humphreys, personal communication, December 6, 2004; *www.nlm.nih.gov/medlineplus/usestatistics.html*).
- In the last week of March 2005, the Association of Cancer Online Resources (*ACOR.org*) delivered 1,524,367 individual e-mails around the globe (G. Frydman, personal communication, April 2, 2005).
- Recent surveys indicate that 80 percent of adult Internet users, or nearly half of Americans over age 18 (about 95 million), say they have researched at least one health topic at some point (Fox, 2005b).
- Two consumer-oriented applications—disease management and patient-centric portals—were included among nine "major HIT trends" (Healthcare Informatics, 2005).
- The major media regularly report e-health topics. For example, patient blogs and their proliferation are a subject capturing media attention; the *Wall Street Journal* called patient blogs "a new and more personal alternative to the plethora of disease-related Web chat rooms, message boards, and e-mail discussion groups" (reported in *iHealthBeat.org*, May 4, 2005).
- President Bush has made it a national policy goal that all Americans will have portable electronic health records, which they control, by the year 2014, and he created an office to coordinate progress on health information technology (Bush, 2004a).
- A RAND Corporation study found that 72 percent of adults sought out information for treatment decisions, and 69 percent of adults used the Internet more often than any other source for health information (RAND Corporation, 2005).

The growing diversity of the e-health market is itself an important sign of its dynamism. The momentum toward e-health now affects nearly every segment of society, albeit to a different extent. For example, the 5 to 7 million enrollees in the My HealtheVet program of the U.S. Department of Veteran Affairs (VA) can view parts of their health records and carry out health-related functions through personally controlled electronic health records (*www.myhealth.va.gov*). Significantly, so can the 1,500 migrant farmworkers enrolled in the California program MiVIA (profiled in the Preface). And every month, more than a third of the 300,000 subsidized housing residents in the United States who use the Beehive (*www.thebeehive.org*), a Web site designed for persons with low literacy, visit its health section—consistently the most trafficked section of the site (S. Brachle, personal communication, March 2005).

Just a few years ago, the "typical e-health consumer" was described as "educated, middle- or upper-income, and an assertive and empowered buyer" (eHealth Institute, 2002, p. 16). Citing 1999 findings of Cyber Dialogue, Inc., Cain, Sarasohn-Kahn, and Wayne reported that "online health consumers behave in ways typical of *New Consumers* (individuals with a certain amount of discretionary income, experience with computers at work and/or at home, and the equivalent of at least 1 year of college education)" (2000, p. 14).

Although younger, better-off consumers continue to predominate in this market, the e-health consumer profile is slowly growing more multidimensional as new channels to e-health tools open and the number and type of stakeholders, intermediaries, and dissemination agents expand. Persistent disparities and the digital divide still require policy attention, but usage trends in the U.S. population are moving toward greater inclusiveness. Today's Internet users, for example, include more seniors, especially the cohort aging into that category (Kaiser Family Foundation, 2005); more Hispanics (*Hispanic Market Weekly*, 2006; Spooner, Rainie, Fox, et al., 2001); more African Americans (Spooner and Rainie, 2000); and more low-income Americans (Cain et al., 2000). In addition, evidence suggests that some traditionally underserved groups, such as seniors, Hispanics, and African Americans, are even more likely than others to seek health information online (Gustafson, Hawkins, Pingree, et al., 2001; Zarcodoolas, Blanco, Boyer, et al., 2002).

Research also suggests that health status is a complex aspect of consumer interest in e-health. One survey classified online e-health users based on health status and found that "the well" comprised 60 percent of all e-health users, "the newly diagnosed" were only 5 percent, and "the chronically ill and their caregivers" were 35 percent (Cain et al., 2000). The researchers report that the "well . . . search for preventive medicine and wellness information in the same way they look for news, stock quotes, and products," whereas the "newly diagnosed . . . search frenetically and cover a lot of ground in the first few weeks following their diagnosis," but do not necessarily become consistent users. The authors call particular attention to the third group—the chronically ill and their caregivers, who "have the greatest potential to affect and be affected by Internet healthcare provision" because they have incorporated chronic illness management into their daily lives and "turn to the Internet for help" (quotations are from p. 1).

Using data from the Pew Internet & American Life Project, Houston and Allison analyzed health status for Internet users who go online for health information (2002). They found that those who rated their health either as fair or poor were newer users of the Internet but tended to use the Internet more frequently and were more likely to use information from online chats.

Consumers also vary in the stimuli causing them to seek out e-health resources. Some do so after learning about them from healthcare practitioners, media advertisements, or friends. Many health educators and healthcare practitioners, rather than producing their own educational materials, refer patients to Web-based resources or download and provide the information.

The concept of "information therapy," the prescribing of targeted information as part of a clinical encounter, has taken hold in healthcare organizations, such as Kaiser Permanente, and information providers, such as the National Library of Medicine. (See Center for Information Therapy [*www.informationtherapy.org*] for one perspective on the information therapy concept.) A significant percentage of e-health end users do not use the technology themselves, but rather come to the resources indirectly through relatives, friends, or other intermediaries ("infomediaries") who serve as caregivers or information sources. Manhattan Research estimated in 2003 that the "zone of influence" surrounding what was then 82 million e-health users extended to 135 million Americans (as reported in the eHealth Institute Summary Report, 2004, p. 13).

Another stream of e-health consumers comes to these tools initially not through personal initiative but in response to organizational programs. This source of momentum is significant in understanding the forces at work in the e-health market. The organizations in question engage their constituents in using e-health tools (developed, purchased, or leased by the organizations) as part of strategies to enhance services, reduce costs, or achieve other program objectives. The dissemination and marketing strategies used by such organizations may provide useful models for future efforts to widen access to and use of e-health tools.

## DIVERSE INTERESTS AND STAKEHOLDERS

The following sketches illustrate the variety of settings in which consumers encounter and use e-health tools, the factors influencing their e-health practices, and the range of e-health functions available. These characters are fictitious and in many ways idealized because many tools in the market do not have the multifunctionality, interoperability, reliability, and quality of the tools described below. The sketches are useful, however, to illustrate key points about e-health activities and the many purposes they could serve for funders, suppliers, intermediaries, and end users. The hypothetical value propositions involved are summarized in Table 4.

- *Ella* is the mother of Nathan, who has autism spectrum disorder. Ella uses a variety of e-health tools to get information about autism; keep a log of Nathan's treatments, behavior, diet, and other factors; and communicate with other parents of autistic children. She is also able to exchange periodic e-mails with the family pediatrician through her health plan's Web site.
- *Carlos* has just been diagnosed with prostate cancer. His doctor mentions several treatment options and, because it is a lot of information to process in

one visit, suggests that Carlos use an e-health tool to systematically consider and decide among his treatment options. The doctor also recommends a Web site that links Carlos to a national network of other men dealing with newly diagnosed prostate cancer.

- *Ed* has diabetes and lives in subsidized housing that was wired for Internet access when it was built. A neighbor who also has diabetes told Ed about the Beehive, a Web site designed for users in affordable housing. Through the Beehive, with his doctor's encouragement, Ed found more information about managing his disease and was able to connect to the American Diabetes Association site easily, where he found an e-health tool he uses to monitor his blood sugar at home. He reports regularly to his doctor, who monitors blood sugar levels and will contact him if a medical intervention is needed. Ed also keeps up with the latest medical research and tips on self-care through listserv bulletins from the Association.
- *Marian* is enrolled in a large health plan. Through its patient portal, which she can view either at home or at the outpatient clinic, she can see parts of her electronic medical record, refill prescriptions, make and change appointments, communicate securely with her physician, and link to health information Web sites recommended by her health plan.
- *Fran* needs to help her mother find a high-quality nursing home and is very concerned about both cost and quality issues. She downloads information from a Government Web site on nursing home costs and quality, and she enters it in a decision-support spreadsheet program that enables her to keep records of her mother's Medicare payments and medical expenses. Fran also uses a personal health record to keep track of her mother's medications, healthcare appointments, and daily blood pressure readings.
- *Hilary* works for a large company that, through its employee wellness program, is offering her financial incentives to lose 30 pounds and get her hypertension under control. The company offers employees free subscriptions to an online health management tool Hilary can use to find scientific information on nutrition and fitness and to keep track of her eating and exercise. Because she finds she needs extra support, especially at night when she tends to snack, Hilary also joins an online community that gives her peer contact around the clock.
- *Rosa* has decided to heed her children's urging that she get a mammogram. With their help, she views an online educational video and downloads illustrated Spanish-language information on mammograms and breast cancer from the kiosk at her community health clinic. Because her reading skills are limited, she appreciates the plain language, illustrations, and spoken narrative available on the kiosk. Her children appreciate the printed materials they can take away and refer to, to help Rosa understand and act on the advice.
- *Gregory* is a sixth-grader who has trouble with impulse control. At school,

his teacher builds into his curriculum a regular time to use a computer program to keep a confidential journal and play instructive computer games. The games help Gregory learn methods for controlling his impulses and getting along with his classmates.

- *Alan* is a college student who's been told he must cut down on his binge drinking if he wants to stay in school. His university provides an e-health tool he can use to record his goals, keep track of his drinking patterns, and maintain a confidential journal. He can enter his weight, number of drinks, and other variables into a calculator to determine what his blood alcohol content would be and the impairments that might result. For a reality check, he can also use the tool to compare his drinking to that of his peers.

As these sketches illustrate, individuals, groups, and organizations have a broad range of interests related to consumer e-health. Healthcare organizations and health plans are major drivers. A growing number of them, and especially large health plans, offer their enrollees portals that afford access to electronic health records, communication, and administrative functions within the institution as well as ancillary health management functions. For these organizations, patient portals can be both an attractive member benefit and a means of reducing administrative costs.

Some healthcare organizations and purchasers offer their enrollees disease management tools to improve care and possibly reduce costs. Disease management tools are an important facet of the Chronic Care Improvement Program of the Centers for Medicare & Medicaid Services (CMS), which will be responsible for nearly half of all healthcare spending by 2014 (Heffler, Smith, Keehan, et al., 2005). CMS also is pilot-testing the Medicare Beneficiary Portal, an example of the kind of portal being offered to enrollees with information on health benefits, clinical content, and clinical transactions. If the CMS pilot is successful, the number and diversity of Americans with access to such portals will increase significantly.

The above sketches also illustrate that healthcare providers and purchasers are not the only public- and private-sector stakeholders in the e-health arena. For example, some large employers offer employees e-health tools as part of strategies to control healthcare costs and enhance employee health. Local, state, and national public health programs offer online prevention and behavior change programs and resources. Some schools encourage students to use e-health tools to help them deal with behavioral and health problems.

Table 4 summarizes the types of stakeholders in the e-health market and some of the interests motivating them. Nonconsumer stakeholders are particularly important for strategies to extend the reach and impact of e-health tools. Alliances and strategies formed around the vision articulated in the Preface should recognize the value propositions for every participant. It is possible that the relative benefits will vary for different stakeholders under different conditions. For example, the potential public health benefits may justify Government investment in e-health tool research, development, and dissemination for underserved populations

*Table 4. Potential e-Health Value Propositions for Major Stakeholders*

| Stakeholder | Benefits Sought From Consumer e-Health |
|---|---|
| Consumers (e.g., patients, informal caregivers, information intermediaries) | • Private, 24/7 access to resources<br>• Expanded choice and autonomy<br>• New forms of social support<br>• Possibility of better health<br>• More efficient record management<br>• Lower cost healthcare services<br>• Avoidance of duplication of services |
| Consumer advocacy and voluntary health organizations (e.g., AARP, American Cancer Society) | • Greater capacity for health management and education for constituents<br>• New communication channels<br>• More efficient service to constituents |
| Employers, healthcare purchasers, and third-party payers | • Healthier employees more capable of health management<br>• Lower healthcare costs |
| Community-based organizations | • Constituents with greater capacity for health management and well-being<br>• Healthier communities<br>• Lower cost healthcare services |
| Clinicians | • Greater efficiency<br>• Better communication<br>• More adherent and satisfied patients |
| Healthcare organizations | • More patient self-care and health management<br>• Lower administrative costs<br>• Improved quality and patient outcomes |
| Public health programs | • A healthier population more capable of self-care and less at risk for avoidable disease |
| e-Health developers | • Sustained use of e-health products<br>• New sources of support for product development and evaluation |
| Industry and commerce | • New advertising vehicles<br>• Wider markets for products |
| Policymakers and funders (public and private) | • Effective means of implementing programs and policies<br>• Cost-containment or cost-reduction strategies<br>• Quality improvement strategies |

even if an uncertain return on investment makes commercial interests reluctant to take the risk.

## CHALLENGES FOR PUBLIC-PRIVATE PARTNERS

This report stresses that e-health tools have the potential to be part of the solution to health disparities and other policy challenges if appropriate e-health resources become available and useful to a larger proportion of the U.S. population than is now the case. Even though "technological innovation is a major driver of the global economy, quality of life, and [individual] health improvement," market forces so far have failed to harness these resources to improve population health (Eng, 2004).

Some observers caution that health disparities could worsen as a result of the uneven distribution of e-health tools or consumers' varying ability to use these resources. Unequal distribution and use of e-health tools could enable some Americans to improve their health and health care while others are left behind (IOM, 2002). Many e-health experts expect that health plans and providers will be the most influential drivers of the adoption of e-health technologies (eHealth Institute, 2005); if so, the large segment of the population without insurance or with no regular source of care will be further excluded from the modern healthcare system.

Public policy and market practices could undermine the benefits for population health in a number of ways. In the private sector, unconstrained commercial uses of health information technology, and in particular unauthorized commercial uses of personal health information, could engender mistrust among healthcare providers and patients. In addition, consumers' use of tools without an evidence base at best could be ineffective and at worst could waste scarce resources or cause harm. As for public policy implications, the severe economic pressures on policymakers discussed in Chapter 1 could generate aggressive, cost-driven policies that force consumers into technology uses and unsupported health decisions that are beyond their current capacities. For all the dynamism in the e-health marketplace and the congruity of public and private interests, it will take a commitment to the vision of this report and new levels of strategic partnership and leadership to produce population-wide health benefits from today's promising conditions. Some specific areas in which strategic efforts are needed are outlined in the following sections.

Even when partnerships offer the opportunity to fulfill value propositions for every participant, they are not likely to occur without leadership. This is especially the case when the ultimate value being sought is the public interest; in that case, the leadership almost certainly must come from the Government (Lansky, Kanaan, and Lemieux, 2005). The Office of the National Coordinator for Health Information Technology, U.S. Department of Health and Human Services (HHS), in collaboration with other HHS agencies and departments in the Federal Government, is tasked with providing leadership in health information technology. Consumer empowerment is already part of the health information technology agenda and could accommodate the vision outlined in this report. Leadership can take many forms, including supporting research and demonstrations, convening stakeholders, participating in coalitions convened by others, setting examples through its own activities, and facilitating strategy development. Public policy should focus on developing and implementing strategies to reach those constituencies already on the margins of the digital mainstream, such as persons who are uninsured, have low income, or have disabilities, as well as on identifying incentives in publicly funded programs.

Exercising leadership in this way would augment and be synergistic with several leading Government programs. For example, in addition to the VA's new e-health tool, My Health*e*Vet, the U.S. Department of Defense has an electronic personal health management system for its constituents, Tri-Care Online. Several HHS agencies, including the National Institutes of Health, the National Library of Medicine, the Centers for Disease Control and Prevention, and the Office of Disease Prevention and Health Promotion, host multitopic, broad-based, consumer-oriented Web sites and provide digital informational materials for the public. The National Cancer Institute has a number of consumer-oriented e-health programs, some described in Chapter 5. Finally, as discussed above, CMS is beginning to offer digital technologies to help Medicare beneficiaries manage their benefits and self-care.

These activities are a good start, but most of these programs target specific constituencies (e.g., Medicare beneficiaries), functions (e.g., health information), or diseases (e.g., cancer). Given the value propositions outlined earlier, there are sound reasons to support connecting diverse governmental activities as part of a comprehensive, coordinated strategy akin to the current electronic health record initiative.

The current work on personal health records (PHRs) by industry and Government, separately and jointly, is likely to have an important impact on the future of consumer-oriented e-health. In addition, this activity provides a model for what can happen through targeted joint efforts. Connecting for Health, a collaborative of more than 100 public and private stakeholders from Government, the information technology industry, and health care, is working to "bring health care into the information age" through technologies such as electronic health records and PHRs (Connecting for Health, 2004).

PHRs are an emerging technology to enable people to manage their health information and healthcare transactions electronically. Although significant challenges need to be resolved with PHRs, some observers envision them as the gateway and possible platform for all consumers' personal health management activities (NCVHS, 2005a).

As noted above, the President increased the visibility and momentum for electronic health records when he set a national goal that most Americans should have electronic health records by 2014. The Office of the National Coordinator of Health Information Technology (HIT) bears major responsibility for advancing the President's goal, and PHRs are one of the goals in the Strategic HIT Framework promulgated in 2004. Former National Coordinator Dr. David Brailer describes the purpose of the office as helping to create the conditions in which the market can deliver health solutions to the nation (Lansky et al., 2005). These activities model the kind of strategic partnerships that will likely be necessary to address the challenges outlined below.

### *Challenge 1: Linking Development, Evaluation, and Dissemination*[1]

The preceding chapters discuss this study's findings about the significant gaps in e-health tool development, evaluation, and dissemination. Chapter 2 outlines the challenges in developing tools for diverse populations. Chapter 3 describes the emerging evidence of the benefits of e-health tools and the fact that the research does not translate into broad use of evidence-based tools outside the laboratory. As Chapter 1 discusses, this study found that the tools in widest use have not been evaluated by unaffiliated third parties, while those that have been the subject of rigorous research often are not widely available. In other words, alignment is lacking between the e-health tools with the best evidence and the ones that most consumers encounter. For example, although the popularity of commercial dieting Web sites may be a sign of the dynamism of the e-health market, questions remain about the scientific basis of the content as well as the short- and long-term behavioral and health effects of the tools.

Researchers and funders report that it is difficult to get evidence-based e-health tools into broad and sustained public use. A major reason for this problem, according to study informants, is the lack of coordinated and balanced funding for development, evaluation, and dissemination, with the bulk of funding supporting only the first two steps. Tools that are developed with Federal and foundation support are generally tested with small, targeted populations.

Funding is not available for sustained dissemination, much less for reaching a significant proportion of the population or for long-term evaluation. Connie Dresser, who coordinates the National Cancer Institute's Small Business Innovation Research program (described in Chapter 5), points out that this leaves unanswered the question of "real-world" effectiveness (C. Dresser, personal communication, September 10, 2003). In addition, an opportunity is missed to obtain empirical information on the factors that support or undermine sustained consumer use. The failure to get tools into circulation particularly affects population groups with the most to gain from a greater investment in dissemination, which is an important policy consideration given that many of the tools designed for underserved

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[1] This section is based on discussions with developers, researchers, and public health professionals in interviews, a special conference call on dissemination issues, and a November 2004 review meeting. See Appendix 2 for a list of participants.

communities are created with foundation or governmental support.

Developers and researchers are a good source of ideas about possible solutions. Study informants point to the need for restructured funding and broader notions of research "success"—in both instances, to include dissemination. They note that as noncommercial developers, most researchers lack the capital and skills to get their tools out to the public. Their isolation from the world of implementers is a major barrier to more effective dissemination of evidence-based tools. Creating a collaboration between these groups, informants say, would require cultural and structural changes within the research field, such as translating technical and scientific jargon into marketing language and reframing rewards so that all stakeholders get a return on their investment.

In addition, developers express interest in learning from the successes of commercial products and applying that learning to getting beneficial tools into broader use. Some cite the pharmaceutical industry, with its sophisticated mechanisms for moving products from inception to market, as a model for a similar "chute" for communication and e-health tools. Fundamentally, the researchers consulted for this project assert that Government and foundation funders should accept more responsibility for the diffusion of products that are developed with their support, provided they are shown to be efficacious. This way, high-quality tools might actually reach the users for whom they were designed.

### *Challenge 2: Building Economic Viability and Sustainability*

Better links among tool development, evaluation, and dissemination could help balance the related goals of expanding markets and raising the standards for e-health tools. This linkage could go a long way toward addressing the sustainability issues that are a common concern of many e-health developers. Sustainable business models are an essential building block in the broad vision for consumer e-health. Government may have to spearhead strategies to reach underserved populations that could benefit from e-health tools but may not initially or ever be able to pay for them. Nevertheless, Government alone cannot underwrite tool development and dissemination on a large scale, so there can be no widespread dissemination and adoption of evidence-based tools without successful commercialization. This was a recurrent theme in conversations during this study, as it is among developers themselves.

e-Health developers are based in public health and public interest organizations, health care, academia, and business as well as in the communication arms of several Government agencies. Their funding sources include grants, investments, and large organizational budgets. As noted, Government and foundation research grants are a major source of financing for tool development and evaluation. After the research and development stage, private-sector developers need realistic business plans to continue production, upgrading, and dissemination. The business models for consumer e-health tools include advertising, sponsorship, licensing, fee-for-service, subscription, and the services of "bricks and mortar" healthcare delivery systems (Eng, 2001, pp. 34-37).

A cross-section of e-health leaders from public health, computer science and technology, health care, academia, and business has been addressing common interests and concerns in eHealth Developers' Summits since 1999 (eHealth Institute, 2002, 2003, 2004, 2005). The summaries of these meetings provide a window on developers' perspectives; issues they, their business partners, and their clients face; and other themes in the e-health environment. In general, a growth in optimism about the viability of e-health can be traced from the time of the 2000 dot-com crash through the ensuing Summit summaries. Nevertheless, the search for sustainability business plans for e-health developers stands out as a persistent concern. As the summary of the 2001 meeting stated, "Strong proof of ROI [return on investment] remains elusive for most eHealth solutions, and realizing tangible financial benefits from eHealth is probably a long-term process" (eHealth Institute, 2002, Executive Summary; see also eHealth Institute, 2005, pp. 30-36).

A fundamental part of the problem is that although consumers are the intended end users of these products, few are in a position to pay for them for a wide variety of reasons. For both large and small developers, there is thus a mismatch between users and purchasers. Even consumers who recognize the health benefits of e-health tools and want to use them generally expect another entity to pay for them (Connecting for Health, 2004). Simply put, the market has not yet identified a uniformly successful price or sales model for consumer information Web sites and other e-health tools.

The information derived from interviews for this study on 40 e-health tools, although not necessarily representative, illustrates the sometimes roundabout route to consumers and the disconnect between payers and end users (see Appendix 1). The interviewees report that consumers—who are by definition the end users of all the e-health tools—pay to use only 9 of the 40, and only 3 tools are exclusively distributed directly to consumers. In some cases, developers produce commercial direct-to-consumer versions as well as others that are made available through business partners. Tools in the latter group usually have more functions, customized to the business partner's specifications. Partners in the categories listed in Table 4 disseminate 37 of the 40 tools in this group. Thus, consumers gain access to them in their capacity as employees, health plan members, national health organization constituents, and so on. Relatively few developers have the funding to conduct rigorous scientific evaluation of their tools; most conduct cost-benefit studies comparing health service utilization, absenteeism, or other variables related to the cost of distributing the tool, to demonstrate their products' ROI for purchasers.

On the subject of the research-dissemination disconnect, eHealth Summit discussions identify integrating research findings into viable real-world products as a particular challenge for developers. The 2004 Summit group voted "lack of expertise to translate research findings into practical product modifications" as the chief reason why there is not more e-health research. This followed the 2003 meeting's call for alliances and partnerships between academic researchers and commercial companies with common target audiences, to speed dissemination and diffusion of findings into marketable products.

A public interest perspective requires that profitability be combined with quality, utility, privacy, continuity, and other values for consumers. Finding commercial models that allow developers and suppliers to satisfy business requirements while also serving the public interest is an important challenge facing policymakers and others who hope to stabilize the market and expand the public benefits of e-health tools. Arguably, the dual goals of market stability and wider reach for e-health tools are synergistic. Opening new markets could increase the financial viability of e-health developers. Seventy percent of the 2003 eHealth Summit participants favored this idea, indicating in a survey that they saw market potential in underserved communities (eHealth Institute, 2004).

Healthcare reimbursement and payment policy is another important part of the solution. The former National HIT Coordinator Dr. David Brailer captured a key attribute of e-health: "Today's reimbursement policies are based on the premise that legitimate care is only done in proximity to a doctor, and that needs to change. Care does not have to be the same place and time as the doctor; it includes daily monitoring, e-mail, and more. Modern policies need to incorporate the consumer in self-management" (cited in Lansky et al., 2005).

## *Challenge 3: Protecting Privacy and Nurturing Public Trust*

Protecting the privacy of personal health information in e-health tools is another "public good" requiring attention from policymakers and private-sector partners. This issue is highlighted here for two reasons: first, the well-documented privacy concerns of consumers, healthcare providers, and others could impede the adoption and use of e-health tools and limit their benefits (California HealthCare Foundation, 2005); and second, the well-being of users is at risk if privacy protections are inadequate.

Surveys show that consumers rate personal health information as one of the two most sensitive types of consumer personal information (along with financial information), and they are concerned about the electronic collection and use of their medical records. Individuals with serious and/or genetically based health conditions express the greatest concern (NCVHS, 2005b). Many consumers fear identity theft as well as discrimination against them in employment, insurance, or other areas based on their health status. Some people fear that their privacy is at risk when they are surfing the Web, and many who use health information Web sites do not share their personal data (Westin, 2005).

People's fears about abuses, especially related to electronic medical records, are not unfounded, as confirmed in the daily newspaper. Policymakers, healthcare organizations, developers, and public-private collaborations take these issues seriously and are working on laws, regulations, and security mechanisms to prevent or at least minimize privacy abuses. Consumers' attitudes toward privacy and electronic personal health information vary widely. Although some people express fear about any electronic processing of health records, others celebrate the benefits of this technology and freely share private information in public online communities. The developer interviews for this project provide anecdotal information about some consumers' practices in this area as well as developers' approaches to protecting privacy. Information from the interviews together with observation of Web sites reinforce the point that consumers exhibit widely ranging attitudes toward health privacy (see Appendix 1).

This area warrants further research into consumer attitudes and practices as work continues to improve laws, regulations, and security mechanisms. The heart of the question before policymakers is how to nurture an atmosphere of justified public trust. Doing so requires establishing adequate security mechanisms and respecting consumers' choices about sharing information in different circumstances. It also involves cultivating in consumers an appreciation for the potential benefits of health information technology—for themselves and their families. As awareness grows about the seriousness of these issues, a number of public and private groups are working on health information privacy and security. They include the National Committee on Vital and Health Statistics Subcommittee on Privacy and Confidentiality, which advises HHS, the HHS Privacy Advocate, the HHS Office of Civil Rights (which enforces the Health Insurance Portability and Accountability Act [HIPAA]), and several university-affiliated institutes.

### Challenge 4. Assuring Quality

The quality of information and tools available on the Internet is an ongoing and unresolved issue in the e-health field. Apart from privacy and confidentiality issues, public trust can be undermined by doubts about the reliability of the information and claims from either commercial or governmental sources. Although health Web sites can be reviewed and accredited by established organizations, such as URAC (American Accreditation HealthCare Commission, Inc.), accreditation remains an underused practice in this sector. The cost of accreditation and an apparent lack of consumer demand for it have resulted in a limited number of sites seeking accreditation (see the list of accredited Web sites at *www.urac.org*).

The research review in Chapter 3 as well as the interview reports in Appendix 1 indicate that researchers are trying to determine consumer behavior toward quality assessment and identify mechanisms to enhance and signal quality to consumers. Quality assessments of e-health tools, however, are an elusive target and depend in large part on editorial processes, judgments about what constitutes reliable and credible sources of information, and an ever-changing body of scientific knowledge about health conditions and their causes, effects, and treatments. Beyond the *Healthy People 2010* objective on the proportion of health Web sites that disclose information to assess the quality of the site and past interest from the Federal

Trade Commission in fraudulent health claims and privacy policies, there has been little public policy attention to matters of information quality on the Internet.

If e-health tools evolve primarily as a part of health plan and provider operations, then quality assurance of the tools may become a routine part of business. Consumer behavior suggests, however, that finding and comparing Internet health resources is a popular activity and one unlikely to be eliminated by the greater availability of provider portals. Consumers may not be clamoring for public action on quality assurance, but quality may nevertheless become a public policy matter if consumers end up choosing questionable tools that result in higher costs and worse health outcomes.

## SUMMARY

This chapter portrays a dynamic e-health arena and identifies the gaps that must be filled to transform it into one from which more Americans can benefit. The goal, as outlined in Chapter 1, is to get appropriate evidence-based tools into wide and sustained use to improve population health. The steps that must be taken to achieve this goal, as outlined in this chapter, include linking e-health tool development, evaluation, and dissemination; building viability and sustainability; protecting privacy; and assuring quality.

This chapter profiles the many interests at play in this environment. The stakeholders who share an interest in consumer e-health include consumers themselves, developers, and researchers as well as healthcare organizations, purchasers, employers, public health programs, and governmental institutions. All are potential participants, in various combinations, in efforts to create the conditions in which many more Americans can enjoy the benefits of appropriate e-health tools. Moving beyond the status quo requires collaboration among stakeholders who see and take action beyond their customary boundaries. This chapter mentions several such collaborations, and Chapter 5 profiles others. A large gap that remains to be filled is leadership and coordination within and between the public and private sectors.

# CHAPTER 5. PARTNERSHIPS FOR MEANINGFUL ACCESS

## INTRODUCTION

This chapter presents several case studies illustrating creative approaches to widening meaningful access to technology and resources in diverse and underserved communities. The examples vary in scope from local to national initiatives, encompassing both health-specific and more general purposes. The programs either already serve as channels for e-health tools or represent potential channels. These examples illustrate ways to address diverse user characteristics and meaningful access issues described in Chapter 2. They also show the effective use of multiple forms of partnership and collaboration discussed in Chapter 4. The strategies profiled here rely on not-for-profit ventures supported by governmental bodies and public interest organizations. Having proven effective in communities outside the digital and economic mainstream, these strategies can complement more standard market approaches. In some cases, they may help create the conditions for a return on investment in health information technology in underdeveloped markets.

The present study confirmed earlier findings that many public and private programs are providing computers and Internet access for segments of the U.S. population that otherwise might not have them (HHS, 2003). However, one of many challenges for those working for equality of opportunity in this area is that although need and gaps can be documented, the data for tracking the progress in meeting the need are limited. This study found that few publicly supported or nonprofit programs have the resources to document the effect of technology access on the intended beneficiaries. Even less is known about user demand for particular content and applications—for example, what might be of greatest interest to diverse user groups in supporting personal health management. This is an important area for additional research and data collection.

The strategies for broadening reach and impact profiled here are:

- Using the existing community infrastructure to provide access and training in underserved communities through
  - Libraries
  - Community technology and community-based organizations
- Implementing a statewide strategy involving multiple partners
- Reaching out to target audiences
- Supporting research involving diverse audiences

## USING THE EXISTING COMMUNITY INFRASTRUCTURE TO PROVIDE ACCESS AND TRAINING IN UNDERSERVED COMMUNITIES

### *Libraries*

Public libraries are the backbone of the traditional information infrastructure. In the last decade or so, they have been refashioning themselves, with major foundation support, to serve as hubs of public computing, especially for people in underserved communities. Thanks to extensive research and documentation, library-based computer programs can inform public computing activities in other settings as well. Libraries are an important and familiar venue for public access computing, especially for people without Internet access at home. They are the third most common place for Internet access for children, after home and school, and the most common access point for low-income and African American children (Kaiser Family Foundation, 2004). Twenty-eight percent of children with disabilities go online from a library, compared to 17 percent of children without disabilities (Kaiser Family Foundation, 2004). Ten percent of all Internet users—14 million Americans—regularly use library computers, which are often the only form of access for low-income users (Bill and Melinda Gates Foundation, n.d.).

Until recently, the potential of libraries as public computing sites was largely unrealized. In 1996, only 28 percent provided public access computers; then, a combination of initiatives raised the proportion to 95 percent by 2003 (National Commission on Libraries, cited in Bill and Melinda Gates Foundation, n.d.). In the same year, the "E-rate" (Schools and Libraries Universal Service Fund) created a $2.25 billion annual fund for discounts on connection costs for schools and libraries. Starting in 1997, the Bill and Melinda Gates Foundation committed $250 million to the U.S. Libraries Program, a new initiative to support public access computing in libraries and to provide librarians with technical assistance training—"the largest gift to U.S. public libraries since that of Andrew Carnegie" (Gordon, Gordon, Moore, et. al., 2003). The program is for libraries in areas with at least a 10-percent poverty rate. By the end of 2003, it had installed about 40,000 computers and trained librarians in about 10,000 communities, in every state and the District of Columbia. Because of these initiatives, few sectors compare to libraries in "going to scale" to bridge the digital divide. A Gates Foundation report states, "Today, if you can reach a public library, you can reach the Internet" (Bill and Melinda Gates Foundation, n.d.).

The Gates Foundation supported a 5-year independent evaluation by the Public Access Computing Center (PACC) of the University of Washington. The report, *Toward Equality of Access*, synthesizes the evaluation research and multiple other data sources in a rich overview of the history, status, and prospects for public computing in libraries (Bill and Melinda Gates Foundation, n.d.). These findings have significance beyond libraries. For example, one PACC study found that youth (who use an average of 4.2 locations for computer and Internet use) "often find themselves as educators when it comes to computer and Internet use"; 80 percent have experience of this kind with adults (Public Access Computing Center, 2003). Study director Andrew Gordon also reports that library patrons use 31 percent of their Internet access to learn about a medical problem (Gordon et al., 2003).

The picture is not perfect, to be sure. Forty percent of libraries have no technical training for staff (Public Access Computing Center, 2004). Library computer users often encounter long lines and limited technical assistance; they may not live close to a library; and all libraries have limited hours. Although libraries have gone to great lengths to accommodate patrons who speak languages other than English, these users are still at a disadvantage because of the limited availability of content in their native languages.

Neither are the gains made to date assured, given local library funding cuts, threats to the E-rate, aging equipment, and the growing demand on limited library staffs. PACC research found that 22 percent of libraries report having difficulty sustaining their public access computing programs. It identified keeping libraries open, retaining Internet connectivity, and increasing library staff training as the three major challenges facing public libraries (Public Access Computing Center, 2004). The Gates Foundation has committed an additional $17 million in challenge grants to help libraries sustain their public access computing programs over the long term. Public libraries join other sectors in having to focus on sustaining the gains made to date, even as they seek ways to expand the reach of their programs.

### *Community Technology and Community-Based Organizations*

Nearly everyone comes to computers and Internet use armed with some form of training or technical assistance, formal or informal, often acquired in a supportive social environment. These factors are typically available to middle- and upper-class Americans through their jobs and educational opportunities. Community-based technology programs are designed for low-income adults and youth who either have no other means of access or prefer the supportive learning environment they find there.

Community technology centers are a major vehicle for the technology access programs of Federal agencies (particularly nonhealth agencies such as the U.S. Department of Education), community-based organizations, other nonprofit organizations, foundations, and the telecommunications industry. These programs take many forms and operate across a continuum of community-based and home-based use, with different organizations and programs working in different domains. The points of entry include low-cost housing, libraries, healthcare facilities, community organizations, and schools.

The typical community technology program offers a combination of open access to computers and structured curricula, classes, and technical assistance to help participants develop their technology skills. The majority of local sponsoring organizations has community development missions and uses technology as a tool to help constituents advance their educations, employability, and job access.

Diversity of funding streams and sponsorship, fluctuations in organizational status, and other factors make it difficult if not impossible to estimate reliably the number of community technology programs in the United States. In general, this study found that the available data are spotty and based on either small programs or large surveys with low response rates.

A few somewhat impressionistic numbers, however, may give some sense of scale. In 2005, the national organization of community technology centers, CTCNet, had 1,200 paying organizational members, a small proportion of the total number of organizations. (A Chicago Web site lists 120 such centers in that city alone.) Extrapolating from her previous research on public computing in Toledo, researcher Kate Williams estimated between 88,000 and 144,000 public access computing sites in the United States, including Government, library, commercial, and nonprofit sites (Williams and Alkalimat, 2002).

Community technology centers are a subset of public access computing that CompuMentor estimates at 33,000 to 56,000 centers. A CompuMentor survey found that about 97 percent of these centers serve low-income populations, 85 percent serve communities of color, and 75 percent serve non-English speakers and people with limited English proficiency (Hoffman, 2003). Using the average of CompuMentor's estimate (44,500 centers), a rough but conservative "guesstimate'" of the number of people reached produces a total of 1,335,000 people.[1] If each of these individuals reaches two to three others in their "zone of influence" posited by Manhattan Research, it is reasonable to project that more than 3.3 million people a year use online resources at community technology centers.

Community technology experts and programs have broad experience in facilitating meaningful access and supplying multiple links to community life. They have created trusted service infrastructures, or use preexisting ones, and have demonstrated viable strategies for working with diverse social groups. They specialize in creating the congenial interpersonal context that diffusion of innovation theory says is important for the adoption of innovations (Rogers and Scott, 1997). Some participants become "infomediaries" for friends, relatives, and neighbors.

As an example of these synergies, One Economy Corporation created an innovative training program that prepares young people age 14 to 19 to serve as "Digital Connectors" in their communities. Through this program, to date, 500 youth have delivered more than 10,000 hours of service to approximately 3,000 families across 11 cities (S. Brachle, personal communication, January 2006). The Learning Centers of SeniorNet (*www.seniornet.org*), which serve another underserved and underconnected group, use a peer training model for adults age 50

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[1] "Guesstimate" based on 44,500 centers with 100 users per center per year, 30 percent of whom seek health information.

and older. Learning Centers around the United States are managed primarily by senior volunteers, with classes taught and coached by volunteer instructors.

Community technology is included as an example of a dissemination strategy because those working in this field target and have expertise in working with the low-income communities that are at greatest risk of poor health and health care and most disconnected from services. These programs are important for public health because they represent an access point through which digital health resources can be extended to the communities likely to experience health disparities. Community technology programs have demonstrated success promoting personal and community economic development, and they can connect the same participants to personal health management resources. At a minimum, their content and dissemination models, research, and conceptual work can inform the development of e-health tools for these groups; at best, they themselves can serve as partners in e-health dissemination strategies.[2] In addition, these programs model participatory approaches and principles from which others interested in involving consumers can learn a great deal. Although not an emphasis in most cases, health applications are among the uses of community technology resources, and they are recognized as a valuable way for participants to improve their quality of life. Extrapolating from data on the general population, 30 to 50 percent of community technology users will use some of their Internet time for health purposes (Bill and Melinda Gates Foundation, n.d.; USC Annenberg School Center for the Digital Future, 2004).

In general, the present study found that the public health and community technology fields seem to be at complementary stages with respect to potential partnerships. Having laid the groundwork in community capacities, the community technology network is expressing interest in broader uses of technology to improve their constituents' lives. Public health programs are searching for new and better ways to reach underserved populations with health promotion and disease prevention tools. Community technology programs have been honing the approaches public health programs need to bridge gaps caused not only by lack of technology but also by economic, cultural, and political factors. For example, community technology consultant Dr. Randal Pinkett of Building Community Technology Partners reports that after the constituents in his Roxbury, Massachusetts, project developed basic computer and Internet skills, they expressed an interest in the health uses of the technology for the second phase of the project (Pinkett, 2002).

Further research is needed to create a comprehensive, reliable national picture of community-based access in relation

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[2] Study informants identified young people, mothers, and possibly seniors as priority target audiences. Regarding priority e-health tool content and purposes, they recommend consumer information and health education, disease management, online support groups, translations of medication instructions, and, above all, help in connecting to health services and health insurance (Conference Call on e-Health and Community Technology Access, May 18, 2004; see Appendix 2).

to other forms of access, provide baseline data on the important issue of broadband deployment, and determine what is needed to strengthen community capacities to support personal health management. However, informants in this field express the view that there are enough pockets of information to start developing strategies for expanding e-health tool access in underserved communities (Conference Call on e-Health and Community Technology Access, May 18, 2004; see Appendix 2). Given the appropriate tools and capacity-building, community technology programs that embrace health applications as a priority service might play a crucial role in widening the access of underserved audiences to useful tools for enhancing their health.

## IMPLEMENTING A STATEWIDE STRATEGY INVOLVING MULTIPLE PARTNERS

Many states have notable programs to broaden technology access to improve citizens' lives. Through One Economy's Bring IT Home public policy campaign, for example, 38 states have amended their housing finance policies to provide incentives or mandates to developers that support the penetration of broadband in affordable housing.[3] The California experience models a statewide community technology strategy with several components. The strategic partners and participants come from national and state-based business, academic, philanthropic, public interest, and advocacy organizations, with the state's large and diverse population groups playing a strong role.

At the center is Computers in Our Future (CIOF, *www.CIOF.org*), a seminal program that helped create a scaffolding, if not an infrastructure, for technology access programs across the state. It was conceived and funded by the California Wellness Foundation to demonstrate the impact of increased technology access on education and employment opportunities for young people in low-income communities. The Wellness Foundation reasoned that education, employment, and economic development are preconditions of health and thus an appropriate investment for a foundation with a wellness mission. In 1997, the Foundation awarded 4-year grants totaling $7.5 million to rural and urban community-based organizations around the state for the establishment of 11 community technology centers.

CIOF is somewhat unusual, and exemplary, among community-based organizations in the thoroughness of its data on the project. By the end of the grant period, the centers had trained 22,500 people in computer use, half of them young people (Fowells and Lazarus, 2001). They successfully reached priority audiences: roughly 80 percent of users are members of racial and ethnic minority groups. The project also produced a set of workable models for introducing technology and its uses to disadvantaged communities. The models involved open access to technology, training and skill building, linkages to employment resources, community resource functions,

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[3] For example, Kentucky law requires that low- and moderate-income housing projects provide home access in order to receive state funding (Henry J. Kaiser Family Foundation, 2004).

and a means of expression for community technology advocacy. Although access to health information was not emphasized, many centers provided it.

Nine of the 11 community technology centers established by CIOF still exist. They share the landscape with other community technology endeavors, some of which started around the same time as CIOF and others of which resulted from it. Money from telecommunications companies is a common funding source for such programs, often mandated as a condition of mergers or other regulatory actions.

In California, an important grantmaking institution is the Community Technology Foundation of California (CTFC), which was created in 1998 by 134 community organizations and Pacific Bell (now part of SBC Communications). CTFC focuses on collaborative efforts "in California's low-income, minority, limited-English-speaking, seniors, immigrant, and disability communities" (*www.ZeroDivide.org*). It funds access programs for a number of target populations—for example, the San Francisco-based Latino Issues Forum (*www.lif.org*), which has programs on health, technology access, civic participation, and sustainable development.

The Community Technology Policy Council, another CTFC grantee, produced a detailed report on access among Asian Americans and Pacific Islanders, its constituency—another well-documented "pocket of information" about community access and use (Community Technology Policy Council, 2004). CTFC also sponsors the Access Fund, which partners with the national Alliance for Technology Access to help organizations eliminate barriers faced by people with disabilities through program assessment, consulting services, technical assistance, and grants.

One focus in California, as elsewhere, is on sustaining the gains made in recent years. Linda Fowells of Community Partners, a Los Angeles-based nonprofit organization active in this area, regards advocacy activities as critically important. She says, "Policy work is the cutting edge of community technology today because that's what will assure sustainability" (L. Fowells, personal communication, March 2004).

Virtually all of the aforementioned state groups are part of the California Community Technology Policy Group, which leverages policy information, training, grassroots advocacy, and lobbying to push for favorable state legislation and regulation. Such efforts have been markedly successful over the last decade. For example, California was the first state to have a set-aside fund for broad digital divide projects. The California Teleconnect Fund, which predates and is broader than the Federal E-rate, makes Internet connection available at half the market rate to schools, libraries, community-based organizations, and healthcare organizations.

In the health sector, the Northern Sierra Rural Health Network demonstrates innovative uses of technology and public policy to promote personal health management in a rural area. Headquartered in Nevada City and funded by the U.S. Department of Agriculture's

Universal Service Fund, it coordinates a telemedicine network that it helped develop in its region. Working with two Stanford University clinician/researchers, the Network piloted a support group for women with breast cancer in two isolated communities, using videoconferencing facilities available in the local medical centers. The group is modeled on Internet support groups, which are not an option in that region because of the lack of high-speed Internet connection.

## REACHING OUT TO TARGET AUDIENCES

This section profiles three outreach programs—two sponsored by Federal agencies and one sponsored by a national nonprofit organization—that combine targeted resources, participatory models, and alliances with community-based organizations.

The National Library of Medicine (NLM) is charged with managing and disseminating scientific health information. It manages scores of Web sites for health professionals and, increasingly, consumers and collaborates with a network of regional libraries. A decision by NLM to join more forcefully in the effort to eliminate health disparities has led in recent years to a significant expansion in its approach to disseminating health information for underserved groups.

NLM intensified its outreach to American Indians in 1997 in an initiative called the Tribal Connections Project. The project, whose ultimate aim is to help underserved Indian communities connect with broad-based health information, has much in common with the community technology programs described above.

Specialized content development is part of the story. NLM sponsors three Web sites for American Indians and Alaska Natives. *TribalConnections.org*, which initially focused on serving the indigenous people of the Pacific Northwest and Alaska, began as a portal to health information sites of interest to healthcare providers and consumers. Recently, it has evolved into also providing its own content, using Native American writers to pen health-related articles that combine Western and Native approaches to healing and healthy living. *TribalConnections.org* also disseminates the articles to Native American publications across the United States.

Having set the goal of expanding its services to Native Americans, an underserved community, NLM invested significant resources in a broad, multifaceted program. The program included assessing local needs and building awareness of the Internet, forging new partnerships with and between the participating American Indian reservations and Alaska Native villages and other organizations, improving the information technology infrastructure and Internet connectivity at 15 of 16 sites, and conducting training sessions with several hundred tribal participants across 13 sites.

The organizers report that “the project demonstrated the key role of tribal community involvement and empowerment and contributed to development of an outreach evaluation field manual and the evolving concept of community-based outreach" (Wood, Sahali, Press, et al., 2003). Project director Fred Wood adds that NLM learned from its tribal work that "the old ways of disseminating health information do not work for reaching underserved population groups. What is needed is a robust multidimensional approach to outreach" (F. Wood, personal communication, October 7, 2004). NLM is now using community-based outreach strategies in many communities throughout the country, as reflected in its *National Library of Medicine Strategic Plan for Addressing Health Disparities 2004-2008* (*www.nlm.nih.gov/pubs/plan/nlm_health_disp_2004_2008.html*). NLM convened stakeholders in a December 2004 symposium to review the plan for community-based health information outreach (*http://medstat.med.utah.edu/symposium/*).

One Economy Corporation (*www.one-economy.com*), a national nonprofit organization based in Washington, DC, uses targeted content as part of a broader strategy to promote meaningful technology access. It identifies the 12 million people living in Government-supported affordable housing and the 5 million living in non-Government-supported affordable housing, as its primary and secondary markets, respectively. The organization makes the "equity case" for widening access and promotes a strong governmental role. For example, it leads a national advocacy effort, Bring IT (Information Technology) Home, aimed at state policy. (Some of its accomplishments are described above.) In addition, One Economy makes the economic case for widening access, pointing out that the 27 million people in affordable housing represent $250 billion in purchasing power. In its words, it seeks to demonstrate "how technology can enhance the interaction between affordable housing residents, nonprofit organizations, local government, and the private sector" (One Economy Corporation, 2004).

One Economy particularly stresses the need of low-income users for local information, noting that "online content has been primarily designed for Internet users who have discretionary money to spend, that is, a highly educated audience that reads at average or advanced literacy levels" (One Economy Corporation, 2004, p. 26). In 2001, One Economy launched the Beehive (*www.thebeehive.org*), a bilingual Web site providing localized "self-help content," including considerable health information, "in languages and at a literacy level that speak to low-income people" (One Economy Corporation, 2004, p. 27). Its literature describes the Beehive as "going significantly beyond the issue of access to technology and addressing the content and culture change it will take to achieve economic outcomes."

To date, localized Beehive sites have been developed for 26 cities and 1 state (Kentucky). Nationally, the Beehive serves more than 300,000 users every month. One Economy stresses home-based, rather than community-based, technology access because of the greater convenience and privacy of operating from home. In what might be called the apotheosis of its approach, 200 new units of affordable housing in the South Bronx were outfitted with a centralized Internet connection and household wireless access capabilities in

2004. The cost of Internet access is built into the rent for these units, and targeted content is available from the Beehive.

Targeted content development also proved essential in serving the inner-city populations of a National Cancer Institute (NCI) program in New York City. The Digital Divide Program (DDP) was NCI's first effort explicitly aimed at finding ways to get digital cancer information to people on the other side of this divide. NCI was motivated by the knowledge that ethnic minority, low-income, and less educated populations bear a disproportionate cancer burden and have limited access to electronic health information.

The purpose of DDP research was to find out more about various groups' interest in and use of cancer information tools to inform future program design. In September 2000, NCI awarded roughly $1 million (total) to four programs, all joint efforts between the Cancer Information Service (CIS) and regional organizations, to test strategies to increase cancer communications in underserved communities. Collectively, the four DDPs addressed all components of meaningful access: appropriate content, equipment provision, Internet access, and skill development and support. Former NCI Program Director Gary Kreps writes that the programs modeled "provocative new community strategies for providing underserved groups of people with access to relevant computer-based information about cancer" (Kreps, 2002).

In New York City, the DDP of the Memorial Sloan-Kettering Cancer Center CIS collaborated with the Verizon Education and Technology Center in Harlem and other community organizations to train program participants. Among other benefits, this helped to raise awareness of the location of public computing access points. Perhaps the most significant feature of the Sloan-Kettering project was its development of an innovative information resource for constituents that combines health information content and practical assistance in the use of online resources.

Concluding that the voluminous cancer information available on the national CIS site was too complex and overwhelming for its target audience, project managers developed a special user-friendly, bilingual Web site for their program. *CancerInfoNet.org* presents information about cancer in an organized and easy-to-read format and provides links to a few selected Government-approved sites for each type of cancer. It also offers Web-based instruction and practice opportunities for using the Internet, along with tips for evaluating Web content. Fourteen other CIS programs around the country are now using *CancerInfoNet.org*.

## SUPPORTING RESEARCH AND DEVELOPMENT INVOLVING DIVERSE AUDIENCES

The Federal and foundation programs described in this section support the translation of research findings into evidence-based e-health tools for consumers, patients, caregivers, and, in some cases, healthcare providers. They are included here because of their emphasis on developing techniques for reaching diverse and underserved audiences.

Among Federal agencies, NCI has played a leading role in furthering health communication in general and e-health tools in particular. In one of its several consumer-oriented initiatives, NCI uses Small Business Innovation Research (SBIR) grants to help develop evidence-based, commercially viable e-health applications for diverse and underserved audiences.[4] The Institute has invested heavily in translating cancer research findings into products that use media technology to reduce cancer risks, provide treatment options, and address the needs of cancer survivors. The SBIR program has a number of notable characteristics, not the least of which is that it is one of the largest programs funding the development and dissemination of evidence-based e-health tools. It uses the rigorous National Institutes of Health (NIH) scientific review process, with peer review panels composed of academic experts and small business owners with experience in public health, communications, or media technology.

SBIR funds eight categories of research, seven of which are for consumers, patients, or caregivers. Among other things, the research projects facilitate changing behaviors associated with cancer risk; support family and individual decisionmaking related to cancer genetics; develop communication techniques for diverse populations; provide interactive programs to help with survivorship and quality-of-life issues; and develop public access systems for cancer education, information, prevention, screening, and assessment.

NCI's SBIR program places strong emphasis on serving high-risk and diverse populations. A number of the tools it has funded use community-based sites to enable access for individuals without home computers—for example, a public access multimedia kiosk with bilingual information on breast cancer for Spanish-speaking women. Grant guidelines stipulate a developmental process that includes end-user participation (through focus groups) in product feasibility testing, design, and evaluation. The guidelines also require two rounds of usability testing, one independently conducted and one using NCI's Usability Lab, with the costs covered by the grant. To date, approximately 75 e-health tools have been developed, tested for usability, and evaluated as to efficacy through NCI's SBIR program and either are now or soon will be in the commercialization stage.

Although decidedly closer to "bedside" than to "bench" from the outset, the SBIR program still has limitations related to sustainability, dissemination, and monitoring effectiveness over the long term. As a partial effort to address this limitation, grantees since 2003 have been required to devise a means of tracking sales and purchaser demographics. A closely related program, the NCI Centers for Excellence in Cancer Communications research initiative, is another major Federal investment in the role of communications

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[4] The small business grants program, established in 1982, combines two funding mechanisms—Small Business Innovation Research (SBIR) and Small Business Technology Transfer (STTR)—both of which are designed to involve small businesses in stimulating technological innovation. Eleven Federal agencies and several NIH Institutes use the mechanism. See *http://grants.nih.gov/grants/funding/sbir.htm* for information on NIH's small business program.

in narrowing the gap between discovery and application and in reducing health disparities.

The Robert Wood Johnson Foundation (RWJF) and NCI cosponsored a research dialogue on online behavior change and disease management in August 2001 (National Cancer Institute and Robert Wood Johnson Foundation, 2001). The principles articulated by meeting participants are the standard ones put forward for communicating with diverse audiences, including tailoring content and assuring usability and appropriate technology access. Participants recommended that forthcoming research identify the salient characteristics—such as culture, literacy, trust of e-health information, and Internet use—that influence interactive health communication for different population groups. These are the same research issues highlighted in the Institute of Medicine report, *Speaking of Health*, which stresses the need for research to determine, first, whether "paying attention to heterogeneity matters," and second, if it does, which health communication interventions are most effective (IOM, 2002).

These principles helped shape RWJF's Health e-Technologies Initiative (*www.hetinitiative.org/*), which began in 2003. The Foundation committed $10.3 million to support research to advance the discovery of scientific knowledge regarding the effectiveness of interactive applications for health behavior change and chronic disease management. The first round of awards, funded through a 2002 call for proposals, included 8 Outcome Evaluation Awards that evaluate specific consumer e-health tools and 10 Methodology and Design Awards, 4 of which relate to consumer e-health tools. The second round of grants, through a 2004 call for proposals, funded eight additional awards of up to $400,000 to study consumer-facing Web portals. One goal of Health e-Technologies is finding out "whether or not these applications improve processes and outcomes of care for culturally diverse groups of patients/consumers."

## SUMMARY

This chapter describes cases and identifies new constituencies for the use of technology and e-health tools in diverse and underserved communities. The strategies involved are:

- Using the existing community infrastructure to provide training and open access in underserved communities through
  - Libraries
  - Community technology and community-based organizations
- Implementing a statewide strategy involving multiple partners
- Reaching out to target audiences
- Supporting research and development involving diverse audiences

These projects illustrate, to varying degrees, principles and attributes that will be important in future initiatives to widen reach and impact. First, all employ comprehensive approaches to achieving meaningful access. Second, they involve a wide number of partners and stakeholders, as demonstrated particularly well in the California example. Third, they use participatory approaches that engage consumers not just as targets and recipients but also as designers of content and services. They are not just *for* but also *by* and *with* diverse communities. The community technology and NLM examples are the most explicit about this approach. Fourth, they offer sustained, continuous services at the community level. Library programs exemplify this attribute, although, as noted, their longevity is not assured. Finally, all these projects leverage significant resource commitments from a range of sponsors, including Federal agencies, industry, and foundations, in each case serving as important vehicles for their sponsors' missions and program objectives.

# CONCLUSION

Today, more and more decisionmakers are interested in e-health tools as critical components of personal health management and healthcare reform strategies. Decisionmakers are seeking viable approaches to reduce healthcare costs, improve the quality of care, and increase consumers' ability to manage their own health. Conditions are favorable for a greater investment in consumer-oriented e-health tools. The technology marketplace is dynamic; the public is increasingly turning to information and communication technologies for a better life; healthcare organizations are adopting and offering health information technology; and Government policy is placing great emphasis on both health information technology and personal health management for consumers. Such activities are now part of everyday news.

Since this study began, the Federal Government has embarked on a major initiative to increase the use of health information technology by healthcare providers and consumers. The creation of the Office of the National Coordinator for Health Information Technology within HHS provides a strategic opportunity for the Federal Government to exercise the kind of leadership called for in this report. Improving population health and personalizing health care—key components of the vision underlying this study—are two of the four goals articulated in HHS' Framework for Strategic Action for health information technology (*www.hhs.gov/healthit/strategicfrmwk.html*). The vision and approaches proposed in the present study should be useful in realizing both the population and personal health goals.

The present study seeks to lay the foundation for a robust, population-wide, and consumer-centric e-health enterprise. It outlines a vision, identifies challenges and opportunities, and highlights strategies for using e-health tools to improve personal and population health. A central message is that no single tool or strategy will work for a national population with highly diverse interests, experiences, conditions, and capacities. This study found that, at present, the well-documented diversity in this country is not well matched by the diversity of strategies and responses in the e-health arena. This is the case for e-health tools themselves as well as the policies, funding, and program priorities that influence their development, evaluation, and dissemination.

Realizing the potential population health benefits of e-health tools requires not only a shift in thinking and strategies but also strong leadership to coordinate marketplace and policy momentum for maximum public benefit. Disparities in access to health information, health care, and technology make it highly unlikely that market forces and fragmented public-sector efforts alone will achieve desired public health goals. Consistent with other

Government initiatives, public-sector engagement in partnerships that harness current consumer trends and align the multiple interests of stakeholders is crucial. The way forward for consumer e-health is to use these partnerships and interests to create and sustain a user-centered strategy that results in e-health tools being available on a much wider scale than is currently possible.

# APPENDIX 1. ENVIRONMENTAL SCAN OF 40 E-HEALTH TOOLS

Between August 2003 and February 2004, project staff conducted an environmental scan of consumer e-health tools in the academic, nonprofit, and commercial sectors. The scan was based on review of two major e-health research programs (the National Cancer Institute's [NCI] Small Business Innovation Research [SBIR] program and the Robert Wood Johnson Foundation [RWJF] Health e-Technologies Initiative); articles and citations in the peer-reviewed social science, biomedical, and public health journal literatures; and recommendations from tool developers and other experts in the field. Project staff identified 40 tools for in-depth investigation. The purpose of the scan was to learn about the major characteristics, intended audiences, and evaluation practices of a range of tools. Examples were sought that are recognized by major research funders, use methodological rigor in their evaluations, have public health significance and commercial viability, and/or are technologically innovative. There was no expectation that this exercise would "cover the waterfront" or collect generalizable information. Inclusion in this exercise does not in any way imply an endorsement or evaluation of the quality or effectiveness of the tool.

For consistency, and to glean as much information as possible, the scan was conducted using a standard instrument (see pages 100-106). Questions were based on theories, methods, concepts, and terminology from the peer-reviewed literature; reports on the state of e-health technologies; and handbooks on health communication research. The questions were pilot-tested with experienced e-health developers and researchers and revised based on their comments and suggestions. The instrument was used to conduct interviews with e-health tool developers and other experts (see Appendix 2 for names of interviewees) and review the tools themselves. Staff also sought out information on the tools in journal articles and other documents that were either publicly available or supplied by the tool developers.

Information was collected on the following topics, using the form at the end of this appendix:

- Functionalities of the e-health tool
- Methods of delivery
- User groups, populations served, and their effect on design and evaluation
- Payer(s) for use of the e-health tool
- Prospective purchasers and stakeholders other than consumers/patients
- Research and evaluation practices, including data elements collected
- Privacy, confidentiality, and security practices

- Mechanisms for dealing with adverse events

The resulting descriptions, presented below, represent a late 2003 and early 2004 snapshot of the e-health phenomenon. That phenomenon is rapidly moving: new technology is routinely being introduced; the market surrounding digital applications is in flux (at least two companies in the interview group were acquired during the short interview phase); and grant cycles begin and end. Nearly all of the interviewees described forthcoming products, services, research, or publications that will change the profile of their tools.

## TOOL FUNCTIONS

All of the e-health tools in this group offer users multiple functions. Counting the "other" category as a single function (which understates the reality), the average tool has more than 5 functions of 10 possible choices. The core function, unsurprisingly, is health information, followed closely by behavior change facilitation. The large number of behavior change/prevention tools is partly accounted for by the presence in this pool of 20 NCI and RWJF grantees. At the time, both of these research programs stressed prevention-oriented projects. Significantly, 24 of the 40 tools offer one or more functions other than the nine specified in the interview form. This reflects the uniqueness and originality of e-health tools. The number of tools offering specific functions is shown, in order of frequency, in the following table.

| Function | Number offering (of 40) |
|---|---|
| Health information | 39 |
| Behavior change | 34 |
| Other (one or more additional functions) | 24 |
| Personal health data entry | 22 |
| Decision support | 21 |
| Social/emotional support | 21 |
| Disease management | 19 |
| Secure provider/patient communication | 17 |
| Risk assessment | 17 |
| Personal health record | 12 |

## DELIVERY METHODS

The "average" e-health tool in this group of 40 uses at least two delivery methods—once again treating the "other" category, for simplicity, as representing a single method. In fact, as with functions, the "other" category is large and diverse and includes several unique devices for collecting and transmitting personal health data. The overwhelming number of e-health tools in the interview group—34 of 40—are delivered through the Internet, either through restricted-access (member/subscriber) Web sites, public Web sites, or a combination. Some tools that were initially developed for delivery via CD-ROM, notably, the Comprehensive Health Enhancement Support System (CHESS), have been converted to the Internet. e-Health tools generally use more than one delivery method. However, in most cases a primary form of delivery (e.g., secure, restricted-access Web sites) is combined with one or more ancillary methods (e.g., e-mail notices).

## AUDIENCES AND AUDIENCE SEGMENTS

The findings show the complexity of e-health audience variables and the many ways developers think about reaching their intended audiences or user groups. The primary strategy used by developers in this group of 40 is audience segmentation. The findings align with the observations made in the Institute of Medicine report, *Speaking of Health*, about the adaptation of health communication for diverse audiences (2002):

- Some tools are developed for narrowly defined audiences (e.g., people older than age 65 with chronic obstructive pulmonary disease [COPD], or binge-drinking college students). Some developers have an array of such specialized tools or modules.
- Some tools are developed for a broad cross-section of users but are subsequently adapted to serve different audience segments (e.g., a Spanish-language version, a module for pregnant women, a chat room for caregivers). The broad cross-section may exist because the tool is available to all comers (e.g., through a public Internet site) or because it is distributed to a restricted but diverse constituency (e.g., the employees of a distributor or health plan enrollees).
- Some tools are developed for a broad (and therefore presumably heterogeneous) user group in a way that focuses on what all users have in common.

## TRANSFERABILITY OF PERSONAL HEALTH INFORMATION

The interviewees were asked what would be required for the user to transfer personal health data (e.g., history of tobacco use, blood sugar, blood pressure) to another organization's application or device. The findings were varied and sometimes ambiguous. Of the 23 tools on which there is information for this question, some respondents focused on users' ability to get their data in any form, including print, while others focused on interoperability issues related to standards and other technical matters. Only 7 tools have technical interoperability with other electronic systems. Another 7 make users' data available to them in print. In general, the answers indicate the distance yet to go to make applications interoperable and to provide alternatives to proprietary approaches.

## PRIVACY, CONFIDENTIALITY, SECURITY, AND HIPAA

For these tools, security and confidentiality protections are generally addressed at the design stage, with a monitoring protocol thereafter. All interviewees in this group indicated awareness and, where needed, detailed knowledge of the Health Information Portability and Accountability Act (HIPAA). This fact is tempered by the reality that the HIPAA Privacy Rule does not apply to many e-health tool providers. The interviews highlighted the limits to privacy and confidentiality protection in online communities, as well as participants' willingness to continue to share despite these limitations. The developers and distributors of open-access e-health tools with chat rooms and listservs make a serious effort to call users' attention to the fact that the confidentiality of their contributions is not protected; theoretically, consumers use these sites with their "eyes open." Participants must register, and the chat rooms in both open- and closed-system e-health tools in this group are monitored, and in some cases moderated by trained people, to minimize inappropriate behavior. For the e-health tools that are distributed as part of closed systems (the large majority in this group), chat room and listserv participants' privacy seems more assured, as a function of the restricted access combined with stringent security measures.

## Research and Evaluation

In-house or self-evaluation is the most common form of evaluation, done for 36 of the 40 e-health tools. Nearly one-half (18) are also evaluated by a nonaffiliated third party (i.e., an independent researcher). Only 10 e-health tools are evaluated by an affiliated third party (e.g., a sponsor or purchaser). Two-thirds of the evaluations (26 of 40) use at least one validated measure. All 40 e-health tools have undergone some kind of formative research. Almost all of the e-health tools (36) undergo process evaluation, described as usability testing or "ongoing feedback" (associated with continuing quality improvement). Some form of outcome evaluation has been conducted on the majority of e-health tools (33 of 40), with 17 e-health tools being evaluated in randomized controlled trials. (This is likely an unrepresentatively high proportion and reflects the requirements of the NCI SBIR and RWJF programs.) Many tools have an individual user feedback mechanism, such as a "comments" box or phone line. Developers report using the feedback to modify the tools on an ongoing basis.

The Federal Government emerged as significant, both as a funder of developmental or evaluation research and as a dissemination partner or purchaser of e-health tools. Some of the leading research and development on consumer/patient e-health (notably, on personal health records and disease management) is being done by Government agencies, including the U.S. Department of Veterans Affairs and the Centers for Medicaid & Medicare Services (CMS). In addition, at least 15 of the 40 tools have Government funding (usually research-related), in addition to several that are purchased by Medicare or Medicaid for enrollee use. As noted, several developers indicated that they see CMS as a potential purchaser of their tools. The need for Federal and foundation research funding can also be inferred from the fact that the only tools being rigorously evaluated are those with grant funding. Several interviewees mentioned that they had applied for research funding but did not receive it, and thus were unable to do the desired level of evaluation.

## PAYERS, PURCHASERS, AND DISSEMINATION PARTNERS

The questions in the instrument focused on payment for tool development rather than on the mechanisms for dissemination. The information collected shows that most developers in this group have multiple funders or purchasers, and that very few are consumers. Consumers pay to use only 9 of the 40 tools in this group, and of those 9, only 3 tools are exclusively made available directly to consumers (i.e., the tools are also disseminated through intermediaries). The following list shows the number of e-health tools in the interview group that fall in each payer or purchaser category.

| Payer/Purchaser | Number of tools (of 40) |
|---|---|
| Government (usually as research support) | 15 |
| Other | 15 |
| Health plans or insurers (includes Medicare and Medicaid) | 13 |
| Healthcare providers | 12 |
| Consumer/patients | 9 |
| Employers | 9 |
| Third-party sponsor (e.g., drug company, device manufacturer) | 8 |

The largest number of e-health tool developers (21) say they see health plans or insurers, including Medicare and Medicaid, as "ultimate purchasers or stakeholders" for their products (consumers/patients are always regarded as the "ultimate end-users"). To evaluate and demonstrate their products' return on investment for purchasers, many tool developers conduct cost-benefit studies to compare health service utilization, absenteeism, or other variables with the cost of distributing the tool.

As noted above, 37 of the 40 tools are disseminated through various dissemination partners, a mechanism used for both for-profit and not-for-profit tools. The partners are in the following categories (with some developers partnering with several):

- Public health organizations
- Schools or childcare facilities
- Healthcare organizations/individual providers
- Employers
- Health insurance companies
- National health advocacy organizations

In these cases, consumers gain access to and experience the tools as a function of their relationship to the distributing entity (e.g., as employees, health plan members, and constituents of a national health organization). Some distribution partners purchase or license the tools and provide them to customers, employees, or members; others distribute the tools as part of healthcare or public health services. Some developers produce both direct-to-consumer and restricted-access versions of their products, with the latter offering more interactive services that are customized to the distribution partner's specifications.

## *Instrument Used to Conduct Environmental Scan for Consumer e-Health Report*

Name: ______________________________

Date: ______________________________

### *A. Sources of information on application or device. (Check all that apply.)*

- ☐ Interview
- ☐ Web site
- ☐ Peer-reviewed literature
- ☐ Self-published report or other non-peer-reviewed document
- ☐ Other (specify) ______________________________

______________________________

### *B. Bibliographic references available?*

- ☐ Yes
- ☐ No

### *C. Brief description of application available?*

- ☐ Yes
- ☐ No

## *I. Description of the application or device*

1. Application title and URL

______________________________

2. Developer organization

________________________________________

3. Division or unit

________________________________________

4. Contact name

________________________________________

5. Contact address, e-mail, and phone number

________________________________________

6. Function of application or device. (Check all that apply.)

☐ Personal health record

☐ Secure provider-patient communication

☐ Health information

☐ Decision support

☐ Social/emotional support

☐ Risk assessment

☐ Behavior change

☐ Disease management

☐ Personal health data

    ☐ Clinician-entered

    ☐ Captured by device

    ☐ Consumer-entered

☐ Other (specify) ______________________________

________________________________________

7. Method of delivery of application. (Check all that apply.)

   - ☐ Public Web site
   - ☐ Member or subscriber only Web site
   - ☐ CD or DVD
   - ☐ Kiosk
   - ☐ Game console
   - ☐ PDA
   - ☐ E-mail or listserv
   - ☐ Bulletin board
   - ☐ Telephone (any type)
   - ☐ Device other than game or PDA
   - ☐ Other (specify) ______________________________

     ______________________________

8. Intended user group or population served? (Examples: ethnic group, gender, age, income, literacy skills)

   ______________________________

   ______________________________

9. Please describe briefly how you take into consideration the characteristics of your intended users in the design and evaluation of your application or device.

   ______________________________

   ______________________________

   ______________________________

   ______________________________

10. Who pays for the use of the application or device? (Check all that apply.)

- ☐ Consumer/patient
- ☐ Healthcare provider
- ☐ Health plan or insurer, including Medicare and Medicaid
- ☐ Employer
- ☐ Third-party sponsor, such as a drug company or device manufacturer
- ☐ Government (as part of access to health care, such as a community health center, or as part of a research project)
- ☐ Foundation grant
- ☐ Other (specify) ______________________________

______________________________

11. Whom do you think of as the ultimate purchaser(s) or stakeholder(s) of your application or device? (Check all that apply.)

- ☐ Consumer/patient
- ☐ Healthcare provider
- ☐ Health plan or insurer, including Medicare and Medicaid
- ☐ Third-party sponsor, such as a drug company or device manufacturer
- ☐ Government (as part of access to health care, such as a community health center, or as part of a research project)
- ☐ Other (specify) ______________________________

______________________________

- ☐ How is this consideration of purchasers and stakeholders reflected in your design and evaluation?

______________________________

12. If, as a result of using your application or device, a user creates an electronic history (e.g., tobacco use, blood sugar or blood pressure levels), what would be required for the user to transfer this information to another organization's application or device, such as a personal health record?

________________________________________

### *II. Application or device research and evaluation*

13. Who has conducted/is conducting evaluations of the application or device? (Check all that apply.)

☐ Non-affiliated third party (example: independent researchers)

☐ Affiliated third party (example: sponsor or purchaser of application or device)

☐ In-house or self-evaluation

☐ Other (specify) ______________________________

________________________________________

14. Does the evaluation use validated measures?

☐ Yes

☐ No

15. Which types of research and evaluation have you conducted on the application or device? (Check all that apply and please provide a brief description of what you did as part of each type.)

☐ Formative research

________________________________________

☐ Process evaluation

________________________________________

☐ Outcome evaluation (note data source)

________________________________________

☐ Adequacy of confidentiality and security mechanisms

________________________________________

________________________________________

16. On which of the following elements are/were data collected as part of the research and evaluation of the application or device? (Check all that apply.)

☐ Cost-effectiveness for individuals, providers, payers, or sponsoring organizations

☐ Utilization of health services

☐ Frequency of use

☐ Intensity of use

☐ Satisfaction

☐ Convenience

☐ Relevance for users' needs

☐ User appeal (likability)

☐ Health status change

☐ Attitude or belief change

☐ Knowledge change

☐ Intention change

☐ Behavior change

17. Please tell us about any other elements that you collect data on as part of the research and evaluation.

____________________________________________________________

18. Given current concerns about patient safety and adverse events, some people hypothesize that the use of some applications and devices could have unintended, harmful effects. Do you have any mechanism for identifying harmful effects that might occur as a result of using the application or device?

____________________________________________________________

____________________________________________________________

19. Users typically have to provide anywhere from "some" to "a lot" of personal information to use an e-health application or device. Do you assess if your application or device is HIPAA compliant? (Check only one.)

☐ Yes, I've done such an assessment.

☐ No, I haven't done such an assessment.

☐ I have determined that the application or device is exempt and does not require such an assessment.

20. Can you suggest other developers/researchers you think I should talk to?

____________________________________________________________

# APPENDIX 2. PROJECT INTERVIEWEES, EXPERTS CONSULTED, AND REVIEWERS

### *e-Health Tool Developers and Researchers Interviewed*

Wendy Angst, M.H.A.
CapMed, a Division of Bioimaging Technologies
e-Tool: PHR (Personal Health Record) and Personal HealthKey
*www.bioimaging.com*

Dennis Ary, Ph.D.
Oregon Center for Applied Science (ORCAS)
General overview of ORCAS products
*www.orcasinc.com*

Sarah Berg
Ripple Effects
e-Tool: Bring It On
*www.rippleeffects.com*

Susan Brink, Dr.P.H.
Healthmark Multimedia
e-Tool: Adventures with the Shady Characters
*www.healthmarkmultimedia.com*

Vesta Brue, M.B.A.
Smoke Signals
e-Tool: SmokeSignals
*www.smokesignals.net*

Simon Budman, Ph.D.
Inflexxion
e-Tool: myStudentBody—Alcohol
*www.mystudentbody.com*

Ginger Carrieri-Kohlman, Ph.D.
University of California, San Francisco (UCSF) School of Nursing
e-Tool: eDSMP (Internet-based dyspnea self-management program)
*www.managesob.org*

Adrian Casillas, M.D.
Geffen School of Medicine, University of California, Los Angeles (UCLA)
e-Tool: Air Aware (IMMEX)
*www.immex.ucla.edu* (background information)
*www.immex.ucla.edu/docs/collaborations/airaware.htm*

Brian Cuffel, Ph.D.
LifeMasters
e-Tool: LifeMasters
*www.lifemasters.com*

Adam Darkins, M.D., M.P.H., F.R.C.S.
Veterans Health Administration
e-Tool: Care Coordination, VHA Telehealth
*www.va.gov/occ*

David Feffer, M.P.H.
Health Dialog Services Corporation
e-Tool: HealthDialog.com
*www.healthdialog.com*

Barry Fortner, Ph.D.
Supportive Oncology Services
e-Tool: Supportive Oncology Services (SOS) information system

Patricia Franklin, M.D., M.P.H., M.B.A.
University of Massachusetts Medical School
e-Tool: RealAge
*www.realage.com*

Gilles Frydman
Association of Cancer Online Resources (ACOR)
e-Tool: ACOR
*www.acor.org*

Harold Goldberg, M.D., M.A.
University of Washington and NuMedics, Inc.
e-Tool: Internet Comanagement Module for Type 2 Diabetes: The Living with Diabetes Project

Alan Greene, M.D., Cheryl Greene, and Beverly Richardson
Greene Ink, Inc.
e-Tool: drgreene.com and drgreene.org
*www.drgreene.com* and *www.drgreene.org*

David Gustafson, Ph.D., M.S., and Fiona McTavish, M.S.
University of Wisconsin
e-Tool: CHESS (Comprehensive Health Enhancement Support System) (overview)
*http://chess.chsra.wisc.edu/chess*

James Hereford, M.S.
Group Health Cooperative, Seattle
e-Tool: mygrouphealth.org
*www.mygrouphealth.org*

John Hsu, M.D., M.B.A.
Kaiser Permanente
e-Tool: *www.kaiserpermanente.org*

Sharmila Kamani
Degge Group
e-Tool: Kidz with Leukemia: A Space Adventure
*www.kidzwithleukemia.com*

Donald Kemper, M.P.H.
HealthWise
e-Tool: Information therapy
*www.healthwise.org*

Matthew Kreuter, Ph.D., M.P.H.
St. Louis University
e-Tool: Reflections of You
*http://hcrl.slu.edu*

Brian Laing, M.S.
Mayo Clinic
e-Tool: MayoClinic.com
*www.mayoclinic.com*

Kate Lorig, Ph.D.
Stanford University Department of Medicine
e-Tool: Diabetes self-management online
*http://patienteducation.stanford.edu*

Howard Mahran
NexCura
e-Tool: NexCura.com, cancerfacts.com, heartfacts.com
*www.nexcura.com*

Tami Mark, Ph.D.
Medstat
e-Tool: SOS (Supportive Oncology Services) Information Services
*www.medstat.com*

Phil Marshall, M.D., M.P.H.
*Web*MD
e-Tool: *Web*MD Health Manager and Personal Health Manager
*www.webmd.com*

Kevin Patrick, M.D., M.S.
University of California, San Diego
e-Tool: PACE I-DP (Patient-centered Assessment & Counseling for Exercise & Nutrition Internet Diabetes Prevention)
*http://paceproject.org*

Ginger Price
Veterans Health Administration
e-Tool: My Health*e*Vet
*www.myhealth.va.gov*

Barbara Rapchak
Leap of Faith
e-Tool: @ne World®
*www.leapoffaith.com/products_oneworld.asp*

Barbara Rimer, Dr.P.H., M.P.H.
University of North Carolina
e-Tool: ACOR
*www.acor.org*

Michael Roizen, M.D.
SUNY Upstate Medical University
e-Tool: RealAge
*www.realage.com*

Daniel Sands, M.D., M.P.H.
Beth Israel Deaconess Hospital/CareGroup
e-Tool: PatientSite, Beth Israel Deaconess/CareGroup
*www.caregroup.org/patientsite.asp*

Dirk Schroeder, Sc.D., M.P.H.
HispaniCare
e-Tool: DrTango
*http://drtango.com*

Skye Schulte, M.S., M.P.H.
HealthGate
e-Tool: HealthGate
*www.healthgate.com*

Ed Sharpless
Healthtrac
e-Tool: MyHealthtrac
*www.healthtrac.com*

Steven Shea, M.D.
Columbia University Division of General Medicine
e-Tool: IDEATel (Informatics for Diabetes Education and Telemedicine) Project
*www.ideatel.org*

Cynthia Solomon
Access Strategies, Inc.
e-Tool: MiVIA.org and FollowMe.com
*www.mivia.org* and *www.followme.com*

Victor Strecher, Ph.D., M.P.H.
University of Michigan
e-Tool: NCI Centers of Excellence, Project 1
*http://chcr.umich.edu*

Paul Tang, M.D.
Palo Alto Medical Foundation (PAMF)
e-Tool: PAMFOnline
*www.pamfonline.org*

Richard Thorp
MultiMedia Systems, Inc.
e-Tool: Cervical Cancer MultiMedia Toolbox for Vietnamese American Women

Armando Valdez, Ph.D.
Valdez & Associates
e-Tool: Breast Cancer Kiosk

Kevin Wildenhaus, Ph.D.
HealthMedia
e-Tool: Balance
*www.healthmedia.com*

Eric Zimmerman, M.P.H., M.B.A.
Relay Health Corporation
e-Tool: RelayHealth
*www.relayhealth.com*

## *General Background on e-Health*

Connie Dresser**,** R.D.P.H., R.M.
National Cancer Institute (NCI)
Small Business Innovation Research Program

Tom Ferguson, M.D.
University of Texas
*The Ferguson Report*

Susan Fussell, Ph.D.
Human Computer Interaction Institute, Carnegie Mellon University

Ed Madara, M.S.
American Self-Help Clearinghouse

Dena Puskin, Sc.D.
Office of Health Information Technology
Health Resources and Services Administration (HRSA)
U.S. Department of Health and Human Services (HHS)

## *Meeting With HHS Staff on Consumer and Patient e-Health Tools*
## *March 3, 2004*

**Purpose**: To consult with HHS staff about the direction and status of the project and identify e-health research projects at HHS

***Participants:***
David Baker, ODPHP, HHS

Cynthia Baur, Ph.D., ODPHP, HHS

S. Scott Brown, M.P.H., Centers for Disease Control and Prevention (CDC), HHS

Mary Jo Deering, Ph.D., ODPHP, HHS

Leslie Hsu, M.P.H., ODPHP, HHS

Susan Baird Kanaan, M.S.W., Consultant

Susan Katz, M.P.H., CDC, HHS

Sonya Lewis, M.A., R.D., CDC, HHS

Karen McCoy, Centers for Medicare & Medicaid Services (CMS), HHS

Cecilia McNamara, Ph.D., National Institute on Drug Abuse (NIDA), National Institutes of Health (NIH), HHS

Susan Newcomer, Ph.D., National Institute of Child Health and Human Development (NICHD), NIH, HHS

Clara Olaya, M.A., CDC, HHS

Erica Talley, CDC, HHS

Margaret Tolbert, Food and Drug Administration, HHS

## *Conference Call on Audience Factors*
## *April 1, 2004*

**Purpose:** To expand on interview findings regarding how e-health tool developers and researchers think about audiences as they develop and evaluate their tools

***Participants:***
Cynthia Baur, Ph.D., ODPHP, HHS

Adrian Casillas, M.D., Geffen School of Medicine, UCLA (written comments)

Sarah Berg, RippleEffects

Simon Budman, Ph.D., Inflexxion

Alan Greene, M.D., drgreene.com

Susan Baird Kanaan, M.S.W., Consultant

Jim Price, M.B.A., DrTango

Suzanne Suggs, Ph.D., M.Sc., HealthMedia

## *Conference Call on e-Health and Community Technology Access*
## *May 18, 2004*

**Purpose:** To explore the role of community technology in expanding access to e-health tools for underserved populations

***Participants:***
Terry Baines, Telehealth Liaison, Alaska Department of Health and Social Services

Cynthia Baur, Ph.D., ODPHP, HHS

Laura Breeden, America Connects Consortium, Education Development Center

Richard Chabran, Community Partners

Ben Hecht, J.D., One Economy

Leslie Hsu, M.P.H., ODPHP, HHS

Susan Baird Kanaan, M.S.W., Consultant

Wendy Lazarus, M.P.H., Children's Partnership

Laurie Lipper, Children's Partnership

Patty Owen, Health Promotion Unit, Division of Public Health, Alaska Department of Health and Social Services

Randal Pinkett, Ph.D., M.B.A., Building Community Technology Partners, LLC

Alice Rarig, Office of Rural Health and Primary Care, Alaska Department of Health and Social Services

Elisabeth Stock, M.C.P., M.Sc., Computers for Youth

### *Draft Report Review Meeting November 22, 2004*

**Purpose:** To review the first draft of the present report

*Participants:*
David Ahern, Ph.D., Health e-Technologies Initiative, Brigham and Women's Hospital

Cynthia Baur, Ph.D., ODPHP, HHS

Sarah Brachle, One Economy

Susan Brink, Dr.P.H., Healthmark Multimedia, LLC

Simon Budman, Ph.D., Inflexxion

Tom Eng, V.M.D., M.P.H., eHealth Institute

Patricia Franklin, M.D., M.P.H., M.B.A., University of Massachusetts Medical School

Susan Baird Kanaan, M.S.W., Consultant

Gary Kreps, Ph.D., George Mason University

Guadalupe Pacheco, M.S.W., Office of Minority Health, HHS

Randal Pinkett, Ph.D., Building Community Technology Partners, LLC

Dirk Schroeder, Sc.D., M.P.H., HispaniCare

Kavita Singh, Ed.M., Community Technology Centers' Network (CTCNet)

Jessica Townsend, Office of Planning and Evaluation, HRSA, HHS

Sandra Williams, M.A., NIH, HHS

### *Other Reviewers of the Report*

Jeffrey Bauer, Ph.D., ACS Healthcare Solutions

Helen Burstin, M.D., Agency for Healthcare Research and Quality, HHS

Jodi Daniel, J.D., M.P.H., Office of the National Coordinator for Health Information Technology, HHS

Connie Dresser, R.D.P.H., R.M., NCI, NIH, HHS

Susannah Fox, Pew Internet & American Life Project

Miryam Granthon, M.P.H., Office of Minority Health, HHS

Linda Harris, Ph.D., NCI, NIH, HHS

Helga Rippen, M.D., Ph.D., M.P.H., Office of the Assistant Secretary for Planning and Evaluation, HHS

### *Research Assistants*

Leslie Hsu, M.P.H., ODPHP, HHS

Omar Passons, M.P.H., ODPHP, HHS

Rhonda Royster, M.P.H., IQ Solutions, Inc.

Sandra Saperstein, M.S., IQ Solutions, Inc.

Eva Tetteyfio, M.H.S., IQ Solutions, Inc.

# Appendix 3. Chapter 3 Literature Review Summary

| Table Reference Number/Authors/Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| **Randomized Controlled Trials** | | | | | | |
| 1. Anderson ES, Winett RA, Wojcik JR, Winett SG, Bowden T. A computerized social cognitive intervention for nutrition behavior: direct and mediated effects on fat, fiber, fruits, and vegetables, self-efficacy, and outcome expectations among food shoppers. *Annals of Behavioral Medicine* 2001;23:88-100. [Overview, Applicability] | 277 adult supermarket shoppers; 96% female, 92% Caucasian, median income $35,000, mean education 14.78 +/- 2.11 years | Nutrition: supermarket computer kiosk | Nutrition for a Lifetime System (NLS): a self-administered, computer-based intervention providing personalized information, behavior strategies, incentives for change, goal-setting, and feedback on specific nutrition behaviors. Contains 15 weekly segments. | Control group: no intervention. Intervention group: interaction with NLS in supermarket | System usage; intake of fat, fiber, fruits, and vegetables; self-efficacy; physical outcome expectations, social outcome expectations | Mean of 10 segments viewed per participant. Intervention group: improved levels of fat, fiber, fruits, and vegetables; higher nutrition-related self-efficacy; physical outcome expectations; and social outcome expectations. More likely to attain goals for fat, fiber, and fruits and vegetables at posttest. Fat goal maintained at followup. |
| 2. Barrera M, Glasgow RE, McKay HG, Boles SM, Feil EG. Do Internet-based support interventions change perceptions of social support? An experimental trial of approaches for supporting diabetes self-management. *American Journal of Community Psychology* 2002;30:637-54. [Overview, Applicability, Key Findings] | 160 men and women with type 2 diabetes; recruited from physician offices. Sample restricted to those who did not have Internet access at home or work; mean age 59, 53.1% women. | Diabetes: home computer with Internet | Diabetes Web site: All had online articles about diabetes. Coach group also had a coach who gave dietary advice and help with goal-setting. Social support group could exchange information, coping, and support through a peer-directed forum, message boards, and real-time chat. Combined group had all of the above. | Participants randomized into four groups: Information Only, Personal Coach, Social Support, Combined Social Support and Coach. Participants were provided with computers and training. Access was restricted to just the resources in the condition to which they were assigned. | Social support | Participants in the Social Support Only condition had the greatest increase in perceived social support, followed by the Combined conditions, then the Coach Only conditions, and finally the Control condition. Only the contrast between the two support conditions and the control condition were significant. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 3. Bernhardt JM. Tailoring messages and design in a Web-based skin cancer prevention intervention. *International Electronic Journal of Health Education* 2001;4:290-7. [Appropriateness, Applicability] | 83 college students; mean age 21.6, 59% female; 86% Caucasian, 8% African American, 2% Asian or Pacific Islander, 1% Hispanic, and 2% other | Cancer prevention: home computer with Internet | Tailored Web page containing messages about outcome expectations of using sunscreen, perceived self-efficacy to use sunscreen, skin cancer risk, high-risk behaviors, barriers, perceived risk, and personal involvement with skin cancer. These derived from more than 30 pieces of data from each participant. Users chose message source, font, and font color. | Control group viewed a generic Web site about skin cancer prevention; Intervention group viewed a Web site that is tailored in both content and design. | Attitudes, risk behaviors, self-efficacy, expected outcomes, barriers, behaviors | More in intervention group reported reading the Web page. Intervention group had trend toward liking the source better. Intervention group followed more links. Control group found their Web page more relevant, while intervention group found Web page more personalized. No difference in self-efficacy to wear sunscreen or expected outcomes of wearing/not wearing sunscreen. No difference at followup to sunscreen-wearing behaviors. Treatment group showed a reduction in two of five barriers. |
| 4. Campbell MK, Honess-Morreale L, Farrell D, Carbone E, Brasure M. A tailored multimedia nutrition education pilot program for low-income women receiving food assistance. *Health Education Research* 1999;14:257-67. [Appropriateness, Acceptability, Applicability, Key Findings] | 378 low-income women, primarily African American women enrolled in the Food Stamp program in Durham, NC | Nutrition: clinic-based computer with interactive multimedia program | Sisters at Heart: Tailored multimedia program using tailored soap opera and interactive "info-mercials" that provide tailored feedback about dietary fat, knowledge, strategies for lowering fat that are based on stage of change, modeling through the soap opera story | Control group: no intervention; Intervention group: one session of Sisters at Heart | Usability, knowledge, stage of change, eating behaviors | 79% rated program as very helpful, 66% would use it again, and 55% said none of the information was new. Intervention group significantly increased knowledge, stage of change, and certain eating behaviors (baking meat and eating low-fat snacks). Both groups lowered their fat intake at followup but did not differ from each other. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 5. Celio AA, Winzelberg AJ, Wilfley DE, Eppstein-Herald D, Springer EA, Dev P, et al. Reducing risk factors for eating disorders: comparison of an Internet- and a classroom-delivered psycho-educational program. *Journal of Consulting and Clinical Psychology* 2000;68:650-7. [Acceptability, Applicability] | 76 female university students, 67% Caucasian, 11% African American, 9% Asian, 7% Hispanic, Latina, 6% multiethnic or other | Eating disorder prevention: home computer with Internet | Student Bodies: an 8-week program designed to reduce body dissatisfaction and excessive weight concerns. It consists of readings, exercises, online journals, and a moderated online discussion group. | Control group: wait-list control; Intervention group 1: Student Bodies along with three in-person sessions and other readings; Intervention group 2: Classroom education using Body Traps, a classroom intervention with a more traditional academic focus. This study attempted to increase adherence through use of motivators, specifically pass/fail grading based on completion of activities. | Compliance measures, body image, and eating attitudes and behaviors | 68% compliance in computer group vs. 57% in classroom group. Greater compliance in Student Bodies group using incentive than in previous studies. Found evidence of dose-response relationship. Computer group had significant reductions in weight/shape concerns compared to controls; at followup, disordered behaviors reduced. No significant effects were found between the Body Traps and wait-list control conditions. |
| 6. Chewning B, Mosena P, Wilson D, Erdman H, Potthoff S, Murphy A, et al. Evaluation of a computerized contraceptive decision aid for adolescent patients. *Patient Education and Counseling* 1999;38:227-39. [Acceptability, Applicability] | 949 adolescent patients in Chicago (96% African American) and Madison (94% white) family planning clinics | Contraceptive decision-making: clinic-based computer program | Aid for "Contraceptive Decision-making Program": user can choose a contraceptive method from a menu of choices, learn how method is used, graphical presentation of effectiveness, assess personal situation for appropriateness of method, method benefits and costs, feedback about barriers, and patient printout to facilitate discussion with clinician. | Control group: has standard clinic visit. Intervention group: interacts with computer program before clinic visit. | Reactions to computer use, contraceptive knowledge, outcome expectations re: birth control effectiveness, adoption of oral contraceptive (OC), discontinuation of OC, pregnancies | All Madison participants and 98% of Chicago participants liked the computer program. Significant increase in knowledge, greater immediate impact on outcome expectations, no effect of computer on length of usage of OC, trend toward reduced pregnancy in Madison but not in Chicago. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 7. Clarke G, Reid E, Eubanks D, O'Connor E, DeBar LL, Kelleher C, et al. Overcoming Depression on the Internet (ODIN): a randomized controlled trial of an Internet depression skills intervention program. *Journal of Medical Internet Research* 2002;4:e14. [Acceptability] | 299 adults with and without depression recruited from a large HMO, matched by age and gender | Depression: home computer with Internet | Overcoming Depression on the Internet (ODIN): a self-paced, skills training program focusing on the acquisition and use of cognitive restructuring techniques | Control group: received a link to the Kaiser Permanente Online home page where they could receive information and were free to receive other treatment as needed. Intervention group received a link to the intervention. | Site usage, depression | Infrequent patient use of the site; found that their population was more seriously depressed than that for which the intervention was designed. No effect of Internet program across entire sample; post hoc analysis showed modest effect among those with lower level depression. Analyses showed no dose-response relationship but limited dose overall. |
| 8. D'Alessandro D, Kreiter C, Kinzer S, Peterson M. A randomized controlled trial of an information prescription for pediatric patient education on the Internet. *Archives of Pediatric and Adolescent Medicine* 2004;158:857-62. [Appropriateness] | 197 parents recruited from a pediatric practice with the majority white, female, and college-educated; 68% had used computer for health information | Health information: home computer with Internet | Specific Web sites on the World Wide Web | Control group: had standard clinic visit. Intervention group: offered computer training and information prescriptions (IPs) of recommended Web sites. Surveyed 2-3 weeks after clinic visit. | Use of IPs | Intervention group used the Internet more for general and child health information. 32% of those in intervention group used the IP. 66.2% of the Internet information resources used by the intervention group were prescribed by the physicians. Compared with nonusers, IP users were more likely to state they would use the IP again in the future and had already recommended the IP to family or friends. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 9. Delichatsios HK, Friedman RH, Glanz K, Tennstedt S, Smigelski C, Pinto BM, et al. Randomized trial of a "talking computer" to improve adults' eating habits. *American Journal of Health Promotion* 2001;15:215-24. [Overview, Acceptability, Applicability] | 298 adults from a large medical practice. Mean age 45.9; 72.1% women; 44.9% Caucasian, 44.6% African Americans, 24.2% educated beyond college | Nutrition: home telephone-linked communication (TLC) system | TLC-Eat: an interactive, computer-based system. Uses computer-mediated digitized human speech over the telephone to ask questions to monitor the patients' behaviors; patient uses keypad to enter answers. This program focuses on improving dietary behaviors. | Control group: received TLC-PA (see Pinto et al., 2002). Intervention group: conversation with the TLC-Eat, enter answers to questions, TLC provides information, suggestions, help with goal setting, etc. | Food intake, stage of change, self-rated diet, intent to change, and confidence in making changes | Intervention group increased by 1.1 serving of fruit, other food groups showed positive trends. Dose-response relationship seen with higher users eating less fat, more fruit and fiber. More subjects in intervention group moved forward in stage of readiness to change for eating fruits and whole grains, but no difference for vegetables, red meat, and whole fat dairy products. |
| 10. Feil EG, Noell J, Lichtenstein E, Boles SM, McKay HG. Evaluation of an Internet-based smoking cessation program: lessons learned from a pilot study. *Nicotine and Tobacco Research* 2003;5:189-94. [Overview, Acceptability] | 370 adult smokers, 72% female, 81% white, 80% at least some college | Smoking cessation: home computer with Internet | Quit-Smoking Network: Internet-based smoking cessation program using structured quit plan, interpersonal support with peers and professionals, anti-tobacco entertainment, library of information | Study used several different Internet and non-Internet recruitment strategies, randomized into one of four incentive and reminder conditions ($10/e-mail, $10/U.S. mail, $20/e-mail, $20/U.S. mail). | Satisfaction with program; how they found the Web site; smoking behavior, cessation, support, cessation self-efficacy, past use of other cessation aids | Most successful recruitment strategy made use of Internet search engines and user groups, with search engines yielding the most participants. Cessation rate at 3 months was 18%. Participants recruited via Internet had higher cessation rates. No difference in response to questionnaires with $10 or $20 incentives. No difference in response to mail or e-mail followup reminders. |
| 11. Finkelstein L, O'Connor G, Friedman RH. Development and implementation of the home asthma telemonitoring (HAT) system to facilitate asthma self-care. *Medical Informatics* 2001;810-14. [Overview, Applicability, Cost Savings] | Asthma patients (did not describe further or provide N) | Asthma: home asthma telemonitoring (HAT) system | HAT system lets user enter data (peak flow, etc.), provides analysis, and points user to care plan, educational components; sends reports to providers. | Describes HAT system, reports on preliminary findings from a randomized controlled trial. | Compliance, test results | Preliminary findings show higher patient compliance to asthma action plans in comparison to control. Lung function test results collected at home were comparable to those collected under the supervision of trained professionals. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 12. Glasgow RE, Toobert DJ. Brief, computer-assisted diabetes dietary self-management counseling: effects on behavior, physiologic outcomes, and quality of life. *Medical Care* 2000;38:1062-73. [Applicability] | 320 adult type 2 diabetes patients, mean age 60; 56% female, >89% white, more than one-half had attended at least some college | Diabetes: clinic-based computer program | Computer program designed to assess dietary patterns, barriers, and supports; then provide tailored feedback and a dietary fat reduction goal | All received one computer interaction at baseline and at 3 months. At 3 months, divided into four groups: basic condition (above). Telephone Followup (TF) also received three to four telephone support/ problem-solving calls between 3 to 6 months. Community Resources (CR) received information about community resources and newsletters between 3 to 6 months. Combined received all. | Used RE-AIM (Reach, Efficacy/ Effectiveness, Adoption, Implementation, and Maintenance) framework to evaluate. Other measures: dietary behavioral outcomes, physiological measures, quality of life, patient satisfaction measures, self-efficacy for dietary change, and use of community resources | The basic intervention allowed showed improvements in eating habits, especially in reducing fat intake; modest improvements in cholesterol and lipid ratios, and small reduction in HbA1c levels. No changes in quality of life or satisfaction scales. Reach=76% of eligible participated. Possible that the TF and CR interventions not strong enough to produce greater change. Adoption=100% of clinics approached adopted this technology . |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 13. Glasgow RE, Boles S, McKay G, Feil E, Barrera M. The D-Net diabetes self-management program: long-term implementation, outcomes, and generalization results. *Preventive Medicine* 2003;36;410-19. [Overview, Acceptability, Applicability] | 320 adult type 2 diabetes patients, mean age 59, mostly novice computer users, recruited from medical practices, 83% limited or no Internet experience | Diabetes: home computer with Internet | Diabetes Web site: All groups had online access to articles about diabetes information. The Peer Support (PS) group also had access to peer support, professionally monitored forum, and electronic newsletters. The Tailored Self-Management (TSM) group also had access to online professional for advice and support two times per week, feedback on intake and collaborative goal setting, tailored strategies to overcome barriers, dietitian question and answer conferences, and blood glucose and dietary databases and graphical feedback. | These results were a 10-month followup study. All received home computers for 10 months and were randomized into one of the three groups. | Dietary, behavioral, biological, and psychosocial outcomes; implementation and process measures | Significant improvements from baseline in all groups on the majority of outcomes; significant changes in fat and fiber intake, psychosocial outcomes, modest for biological outcomes; PS condition showed greater increase in support measure. No differential effect of TSM condition. Decline in usage of site over study period. PS group showed most logins, followed by TSM, the basic condition. Reach=62% eligibles. Adoption=100% of clinics, 88% of doctors |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 14. Green M, Peterson S, Baker M, Harper G, Friedman L, Rubinstein W, et al. Effect of a computer-based decision aid on knowledge, perceptions, and intentions about genetic testing for breast cancer susceptibility: a randomized controlled trial. *Journal of the American Medical Association* 2004;292:442-52. [Acceptability, Applicability] | 211 women with personal or family histories of breast cancer from six U.S. medical centers; 74% <50 years old, 56% college educated, 93% white, >63% used computer sometimes or often | Cancer: clinic-based computer program | Breast Cancer Risk and Genetic Testing Program: interactive CD-ROM designed to help women make informed decisions about genetic testing. Contains information about who is at risk, how genes affect risk, and pros and cons of testing. Program is self-paced and user-driven. | Control group: has standard genetic counseling appointment. Intervention group: interacts with computer program before genetic counseling appointment. | Knowledge, perceived risk, intention to undergo genetic testing, satisfaction with decision, state of anxiety, satisfaction with intervention | Both groups increased knowledge from baseline level with significant increase in knowledge seen in low-risk women in intervention group as compared to low-risk controls. Greater benefit in women with less education. Overall absolute risk perception high at baseline and reduced in both groups after intervention with greatest reduction in low-risk women in control group. Significant reduction in intention to get testing in low-risk women in both groups. Actual testing did not differ by group. Both groups satisfied with decision. Mean anxiety within normal limits in both groups. Both groups liked interventions; more in computer group felt it made good use of their time. |

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| 15. Gustafson D, Hawkin R, Pingree S, McTavish F, Arora N, Mendenhall J, et al. Effect of computer support on younger women with breast cancer. *Journal of General Internal Medicine* 2001;16:435-45. [Overview, Applicability, Key Findings] | 246 newly diagnosed breast cancer patients under age 60; 74% white, 22.4% African American, 3.6% other persons of color | Cancer: home computer connected to central server | Comprehensive Health Enhancement Support System (CHESS): contains 11 tools that provide information, decisionmaking tools, and support services | Control group: received a breast cancer book. Intervention group: received CHESS. | System usage, patient outcomes, social support, information needs, participation in health care, quality of life | Used CHESS 155 times/26 weeks of study. Caucasian women spent more time using discussion group, women of color spent more time using the decision services. Outcomes at 2 months: CHESS group higher on information competence, level of comfort with participation in health care, confidence in their doctor. No change in quality-of-life measures. After 5 months, CHESS group higher on social support, information competence. Participation in healthcare measures no longer significant. No change in quality-of-life measures at either point. Interaction effects show greater benefits for women of color, uninsured, less educated. |
| 16. Harvey-Berino J, Pintauro SJ, Gold EC. The feasibility of using Internet support for the maintenance of weight loss. *Behavior Modification* 2002;26:103-16. [Acceptability, Applicability] | 46 overweight adults recruited from newspaper ads; 80.4% female, mean age 46.3, 91% at least some college, predominately white | Weight loss: home computer with Internet | The Internet-based maintenance condition consisted of biweekly chats, self-monitoring records, video clips of the therapist introducing topic for discussion in chats, e-mail contact from therapist, message boards, and unstructured chats | All participated in 15-week in-person behavioral weight control intervention and then randomized into three maintenance conditions: in-person therapist-led, Internet therapist-led, and no treatment control. Both conditions met biweekly for 22 weeks using same content. | Satisfaction, attendance, weight loss | In-person therapist-led participants were more satisfied and more likely to attend meetings, but no difference between attrition, submission of self-monitoring data, or peer support contacts between intervention groups. No difference in weight loss between intervention groups (may be due to small sample size, inadequate computer systems that did not allow users to access all features). |

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| 17. Irvine AB, Ary DV, Grove DA, Gilfillan-Morton L. The effectiveness of an interactive multimedia program to influence eating habits. *Health Education Research* 2004;19:290-305. [Acceptability, Applicability] | 229 subjects recruited from a hospital system in Colorado and 288 subjects from an international corporation in Illinois; 85% Caucasian, 73% female, mean age 43, almost 90% college educated | Nutrition: work site computer with interactive multimedia program | This program focused on improving nutrition behaviors. It used video narrators targeted to the users' demographic to provide guidance and support and videos of role models and testimonials to encourage positive behavior change and increase self-efficacy. Program was tailored by gender, content interests, race, and age. Main menu choices included eating strategies, recipes, barriers to healthy eating, assessment of eating habits, information center, and quick tips. | Participants from both sites matched on demographics. Pair then randomized into intervention or wait-list control. Data collected from both groups after intervention and then after wait-list control group used the intervention. | Fat eating habits and behaviors, fruit and vegetable consumption, healthy eating behaviors, stage of change, attitude toward healthy eating, intention, and self-efficacy | Spent an average of 35.75 and 32.09 minutes during the first session. Only 14.7% and 12.07% returned for a second visit, and only 7.5 and 1.7 returned a third time. Most users viewed adding fruit, vegetables, and fiber, then making low-fat food choices. Statistically significant differences found in fat eating habits, fruit and vegetable consumption, program behaviors, self-efficacy, attitude, intent to decrease fat, and stage of change between control and intervention at 1 month, between wait-list control after intervention. Changes in intervention group maintained 1 month after. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 18. Krishna S, Francisco B, Balas A, Konig P, Graff G, Madsen R. Internet-enabled interactive multimedia asthma education program: a randomized trial. *Pediatrics* 2003;111:503-10. [Applicability, Cost Savings] | 228 children with asthma and their caregivers, younger than age 18, with asthma diagnosis seen in a pediatric pulmonary clinic. Caregivers–88% females, 90% white, 6% African Americans, 4% of other ethnic origins, 44% had high school education, 37% had 1 or more years of college, 9% had junior high school or less | Asthma: clinic-based computer program | IMPACT Asthma Kids CD consists of vignettes about asthma, environmental triggers, quick-relief and control medicines, and strategies to control and manage asthma. It has animated lessons, real-life scenarios, graphic templates. The program tracked educational progress of each child and generated reports re symptom level and medication use. | Control group: traditional asthma education group. Intervention group: received traditional and additional education through computer. Implemented more than three clinic visits. | Knowledge, health outcomes, healthcare use | The IMPACT program significantly increased asthma knowledge of children and caregivers, decreased asthma symptom days, and decreased the number of ER visits. The intervention group used a significantly lower average dose of inhaled corticosteroids at visit three. Asthma knowledge of all 7- to 17-year-olds correlated with fewer urgent doctor visits and less frequent use of quick-relief medications. ER visit savings: $907.10 per child in the intervention group; $291.40 per control group; reduced school absences–indirect savings realized by working parents and employers; reduction in medication. |
| 19. Lieberman D. Management of chronic pediatric diseases with interactive health games: theory and research findings. *Journal of Ambulatory Care Management* 2001;24:26-38. [Applicability] | 14 children age 8-13 with asthma | Asthma: clinic-based computer program | Bronkie the Bronchiasaurus computer game | Control group: watched a video about asthma; intervention group: played Bronkie. | Self-efficacy | Self-efficacy for asthma self-management increased for game group, decreased for video group. |

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| 20. Lieberman D. Management of chronic pediatric diseases with interactive health games: theory and research findings. *Journal of Ambulatory Care Management* 2001;24:26-38. [Applicability, Cost Savings] | 59 children age 8-16 with diabetes | Diabetes: home computer with interactive multimedia program | Packy and Marlon, an interactive computer game for diabetes self-care and disease management. Players learn about self-care and social situations. They help character monitor blood glucose, take insulin, eat balanced meals, etc. | Control group: given entertainment pinball video game with no health content. Intervention group: given Packy and Marlon. Both groups told they could play as much or as little as they wished. | Satisfaction, self-efficacy, communication, self-care, healthcare utilization | Intervention group liked the game as well as the control group liked theirs. Increased diabetes-related self-efficacy, in communication with parents about diabetes, and in daily diabetes self-care. By the end of 6 months, intervention group experienced a 77% drop in diabetes-related urgent care and ER visits, an annualized decrease of two urgent visits per patient per year. No decline in control group who remained at 2.4 urgent visits per year. |
| 21. McKay H, Glasgow R, Feil E, Barrera M. Internet-based diabetes self-management and support: initial outcomes from the Diabetes Network Project. *Rehabilitation Psychology* 2002;47:31-48. [Acceptability, Applicability] | 160 type 2 diabetes patients from 16 primary care offices; 75 men and 85 women; mean age 59, 25% with college degree | Diabetes: home computer with Internet | All received baseline program of access to information about diabetes. The Personal Self-Management (PSM) group had coach to work on dietary goals, online blood glucose tracking and graphing system with real-time feedback. The Peer Support Condition (PSC) had peer-directed forums for communication and support, information exchange. The Combined Condition (CC) had access to all of the above. | All received home computers for 10 months and were randomized into one of four groups: information only, PSM coach condition, PSC, or CC. | Web site activity, physiologic, diet and eating behavior, and mental health status | Little change in physiological measures; general improvement in dietary practices, substantial reduction in fat intake. PSC and CC had larger reductions in cholesterol; PSC and PSM had greater improvement in quality of life; PSM and CC had more logins than other conditions. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 22. McKay HG, King D, Eakin EG, Seeley JR, Glasgow RE. The Diabetes Network Internet-based physical activity intervention: a randomized pilot study. *Diabetes Care* 2001;24:1328-34. [Acceptability, Applicability] | 78 adults with type 2 diabetes; recruited by postings to diabetes-specific usenet groups, listservs, Web sites, and online communities; mean age 53; 53% female; 82% Caucasian; 50% college grads; 62% employed full time | Diabetes: home computer with Internet | D-NET Active Lives Program: Internet-based supplement to usual care that focuses on providing support for increasing physical activity (PA) including goal-setting, personalized feedback, identification and strategies to overcome barriers, online "personal" coach, peer support and online chat, online database for personal PA. | Control group: Internet-based information-only condition; Intervention group: access to intervention Web site | Process measures, minutes of PA per week, depressive symptomology | No significant change in depressive symptoms. Overall moderate improvement in PA levels in both groups, no significant between-group differences in PA. Further analyses showed that more frequent site users in intervention group derived greater benefits in PA that were not seen in control group. Steep decline in usage in both groups during the course of study. Those in intervention group more satisfied than control. |
| 23. Napolitano MA, Fotheringham M, Tate D, Sciamanna C, Leslie E, Owen N, et al. Evaluation of an Internet-based physical activity intervention: a preliminary investigation. *Annals of Behavioral Medicine* 2003;25:92-9. [Overview, Acceptability, Applicability] | 65 sedentary adult hospital employees; 86% female, 14% male; 91% Caucasian; 92% skilled and confident using the Internet | Physical activity: home or work computer with Internet | Web site tailored by stage of change for physical activity and includes Activity Quiz, Safety Tips, Becoming Active, Physical Activity and Health, Overcoming Barriers, Planning Activity, Benefits of Activity, links to other sites, plus 12 weekly e-mail tip sheets. | Control group: wait-list control; Intervention group: used Web site plus 12 weekly e-mail tip sheets | Physical activity stage of change, physical activity, computer use | At 1-month follow-up, intervention group had progressed stage of readiness, had significant increases in moderate minutes and walking minutes vs. control. At 3-month followup, difference in moderate activity not significant, walking minutes still significant. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 24. Neighbors C, Larimer ME, Lewis MA. Targeting misperceptions of descriptive drinking norms: efficacy of a computer-delivered personalized normative feedback intervention. *Journal of Consulting and Clinical Psychology* 2004;72: 443-7. [Overview, Applicability] | 252 heavy drinkers (four to five drinks in one sitting in previous month), college students. 104 men, 148 women, mean age 18.5, 79.5% Caucasian, 7% Asian American, 6.8% other | Alcohol: lab-based computer program | Intervention provided personalized normative feedback on alcohol consumption delivered by computer. Once baseline assessment completed, user received feedback on screen and print copy. Feedback contained information about how much they drank, how much they thought others drank, and how much typical students actually drank. | Control group: no intervention.<br>Intervention group: interacted with computer program. | Perceived drinking norms, drinking behavior, social reasons for drinking | Intervention had small effects on drinking and medium effects on misperceptions in drinking norms at both 3- and 6-month followup. Changes in perceived norms were responsible for reduced drinking behavior. Social norm interventions appear to be more effective for those who drink for social reasons. |
| 25. Oenema A, Brug J. Feedback strategies to raise awareness of personal dietary intake: results of a randomized controlled trial. *Preventive Medicine* 2003;36:429-39. [Appropriateness, Applicability, Key Findings] | 304 adults who were students and employees of adult education centers in the Netherlands; mean age 44; 60% female; 47% had university degree or higher professional training | Nutrition: classroom and office-based computer with Internet | Web-based computer-tailored nutrition education session on personal awareness and intentions related to intake of fat, fruit, and vegetables. Program contained four sections: fat, vegetables, fruit, and recipes. In each section, relevant questions appeared, then user received feedback that included how user's computed scores compared to recommended levels. | Control group: received printed nontailored nutrition letter and brochures. Self-test group: used print self-assessments; Intervention group: used the computer-tailored intervention for one session. | Food intake, awareness of personal intake levels, attitudes, self-efficacy, usability | Those in the tailored group had more realistic self-rated fruit intake and self-rated fat intake, greater intention to decrease fat intake and increase vegetable intake than other groups. Those with less education in tailored intervention had more realistic self-rated fat intake than others. Those in tailored group more significantly reported that they had changed their opinions about their dietary habits and intention to change their diets. Tailored program was more likely to be used again than other interventions. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 26. Oenema A, Brug J, Lechner L. Web-based tailored nutrition education: results of a randomized controlled trial. *Health Education Research* 2001;16:647-60. [Appropriateness, Acceptability, Applicability] | 200 adults recruited from adult education institutions in the Netherlands; mean age 44; 62% female; 47% had college degree | Nutrition: classroom and office-based computer with Internet | Web-based computer-tailored nutrition education session on personal awareness and intentions related to intake of fat, fruit, and vegetables. Program contains four sections: fat, vegetables, fruit, and recipes. In each section, relevant questions appear, then user receives feedback that includes how user's computed scores compare to recommended levels. | Control group: received general nutrition information letter. Intervention group: interacted with the computer program for one session. | Food intake, awareness of personal intake levels, attitudes, self-efficacy and stage of change, usability | Significant differences in awareness of self-rated fat intake compared to others and intention to change were found between intervention and control at posttest. Tailored intervention was better appreciated, rated as more personally relevant, and had more subjective impact on opinion and intention to change than general nutrition information. Both groups read most of information and rated them attractive to read. Tailored program was more likely to be used again and rated information as more personally relevant and newer to them. No effect of computer literacy on perceived attractiveness of computer program; however, those with lower computer literacy also reported that the program was more difficult to use. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 27. Pinto BN, Friedman R, Marcus BH, Kelley H, Tennstedt S, Gillman MW. Effects of a computer-based, telephone-counseling system on physical activity. *American Journal of Preventive Medicine* 2002;23:113-20. [Overview, Acceptability, Applicability] | 298 adults from a large medical practice. Mean age 45.9; 72.1% women; 44.9% Caucasian, 44.6% African Americans, 24.2% educated beyond college (same sample as Delichatsos et al., 2001) | Physical activity: home telephone-linked communication (TLC) system | TLC-PA: a program designed to increase physical activity in adults. System inquires about current levels of activity, intentions, and whether they have met goals then tailors feedback to stage of motivational readiness. System asks users to set a task for themselves. Users call system each week. | Control group: received TLC-Eat. Intervention group: received TLC-PA. | Physical activity, stage of motivational readiness for physical activity | Intervention group had greater percentage of individuals meeting recommended levels of moderate or vigorous physical activity at 3 months, but not significant at 6 months. At 3 months, a significantly greater number of intervention group in action, but results were not maintained at 6 months. Fewer calls to TLC-PA as compared to TLC-Eat. Usage declined over the intervention period. Number of calls to the system did not predict outcome—no dose-response. |
| 28. Proudfoot J, Goldberg D, Mann A, Everitt B, Marks I, Gray JA. Computerized, interactive, multimedia cognitive-behavioural program for anxiety and depression in general practice. *Psychological Medicine* 2003;33:217-27. [Overview, Applicability] | 167 Adults recruited from general medical practices in England with anxiety, depression, or mixed anxiety/ depression; mean age 44; 88% Caucasian | Depression and anxiety: clinic-based computer with interactive multimedia program | Beating the Blues: interactive multimedia program of cognitive-behavioral techniques; also includes homework projects. Has one introductory and eight 50-minute treatment sessions; expected to be used weekly. | Control group: received treatment as usual. Intervention group: received treatment as usual with exception of no face-to-face counseling or psychological intervention and interaction with computer program. | Depression, anxiety, work, and social adjustment | Intervention group showed significantly greater improvement in depression and anxiety compared to treatment as usual by the end of treatment and at 6 months' followup. Mean scores of depression and anxiety fell to almost near-normal levels. Also showed improvement in work and social adjustment. |

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| 29. Reis J, Riley W, Lokman L, Baer J. Interactive multimedia preventive alcohol education: a technology application in higher education. *Journal of Drug Education* 2000;30:399-421. [Applicability] | 643 undergraduates; 39% male, 61% female; 64% Caucasian, 15% African American, 11% Asian, 7% Hispanic | Alcohol: classroom computer-based program | CD-ROM with video, music, text, graphics, animations; simulations allow user to practice making choices; also addresses erroneous perceptions, communication skills and assertiveness, and physiological and behavioral consequences of alcohol. | Control group: no treatment. Traditional education group: received classroom education or classroom exercises. Intervention group: interacted with program. | Expectations, efficacy, peer norms, satisfaction | Intervention group significantly more knowledgeable about the symptoms of alcohol overdose; what to do on behalf of a friend in this condition; how to intervene with a friend who has been drinking too much; interplay of blood alcohol concentration, time, and amount; effects of alcohol on judgment and control. Greater intention to try to change their behavior to become more safe and in control in situations involving alcohol. The intervention group rated their educational experience more favorably than the traditional education. |
| 30. Ross S, Moore L, Earnest M, Wittevrongel L, Lin C. Providing a Web-based online medical record with electronic communication capabilities to patients with congestive heart failure: randomized trial. *Journal of Medical Internet Research* 2004;6:e12. [Applicability, Cost Savings] | 107 patients with heart failure in a specialty practice; needed to have Internet experience, but were not required to have Internet access | Heart disease: home computer with Internet | SPPARO (System Providing Access to Records Online): Web-based electronic medical record, educational guide, messaging system enabling e-communication between the patient and staff | Control group: treatment as usual. Intervention group: treatment as usual and SPPARO | Satisfaction, health status, and self-reported compliance were done at baseline, 6 months, and 1 year; system usage, message volume, utilization of clinical services, and mortality | Trend for better satisfaction with doctor-patient communication. No difference in self-efficacy. Significant improvement in general adherence to medical advice. Increased emergency department visits in intervention group, but did not seem to be related to use of SPPARO; no difference in hospitalizations or mortality; no adverse effects reported. Use of SPPARO was highest in first 3 months, then leveled off. Electronic messages appeared to supplement rather than replace telephone messages. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 31. Sciamanna CN, Clark MA. Effects of a fingerprint reader on survey responses of primary care patients. *Journal of Health Psychology* 2003;8:187-92. [Overview, Acceptability] | 76 adults; mean age 36.2, 80.3% female, 42.5% greater than high school education, 35.5% nonwhite, 5.3% Hispanic | Health information: clinic-based computer program with fingerprint reader | The fingerprint reader can be used to authenticate a user. It does not require use of standard identifying data, passwords, or ID cards. | Control group: did not have fingerprint scanned before using computer-based health screening.<br>Intervention group: had fingerprint scanned, then used computer-based health screening. | Attitudes about the fingerprint reader, general health screening | Those who used the fingerprint screener reported poorer health status and lower levels of fruit and vegetable intake as compared to controls; therefore, did not seem to be underreporting as a result of fingerprint screener. No differences between groups in reports of other medical conditions, body mass index, physical activity, current smoking or drinking. No difference in groups in comfort using a computer. The intervention group reported fewer concerns about the fingerprint reader. |
| 32. Smith L, Weinert C. Telecommunication support for rural women with diabetes. *Diabetes Educator* 2000;26:645-55. [Applicability] | 30 women with diabetes living in rural Montana; mean age 46.7 years, 60% employed; only 2 had computers that could load the software, and the rest were loaned computers. | Depression: home computer with Internet | The program consisted of four components: conversation (open chat), mailbox (private exchange between two members or member and educator), health chat (chat with a diabetes educator), and resource rack (information about diabetes). All communication was asynchronous. | Control group: wait-list control.<br>Intervention group: received computers and access to online community for 5 months. | Usage and satisfaction, social support, quality of life, life stresses, adaptation to illness | Group averaged 63.8 minutes/month; most time in first month and then usage decreased. Conversation area most widely used. No difference in psychosocial adjustment to illness or quality of life. 77% said project provided a great deal of support; 12 said it gave them a significant sense of connectedness. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 33. Tate DF, Jackvony EH, Wing RR. Effects of Internet behavioral counseling on weight loss in adults at risk for type 2 diabetes: a randomized trial. *Journal of the American Medical Association* 2003;289:1833-6. [Overview, Acceptability, Applicability] | 92 overweight adults at risk for diabetes; recruited from newspaper ads or from clinic; mean age 48.5; 90% women; 89% white | Weight loss: home computer with Internet | Basic Internet program provided tutorial on weight loss, new tip and link each week, directory of selected Internet weight loss resources, message board, e-mail reminder to submit weight and weight loss information. The intervention group received counseling and feedback via e-mail that was based on submitted food and exercise diaries. | Control: basic Internet program. Intervention: basic Internet program plus e-mail counseling | Web site usage, body weight, waist circumference, physical activity, and food intake | Login frequency decreased for all groups over the course of the intervention. Intervention group used site more at all time periods than control. Significantly more weight loss and waist circumference decrease in the intervention group. 4.4 kg lost after 1 year in intervention group. |
| 34. Tate DF, Wing RR, Winett RA. Using Internet technology to deliver a behavioral weight loss program. *Journal of the American Medical Association* 2001;285:1172-7. [Overview, Acceptability, Applicability] | 91 overweight adults recruited through an employer's Intranet Web site; 81 women, 10 men; mean age 40; 78% control group and 89% intervention group Caucasian | Weight loss: work site computer with Intranet | Web site reviews basic information related to weight loss and includes resources about diet, exercise, self-monitoring, and other behavioral resources. | All received initial session with a psychologist. Control group: Internet education/ resources Web site. Intervention group: Internet education, 24 behavioral lessons via e-mail, weekly online submission of self-monitoring diaries with individualized feedback from a therapist, and an online bulletin board. | Web site usage, body weight, waist circumference, physical activity, and food intake | Login frequency significantly correlated with weight loss. Intervention group logged in more frequently than control group throughout the study, although both groups showed attrition after month 3. Behavior therapy group lost more weight than control group. More in the intervention group achieved 5% of total weight loss goal. Greater decrease in waist circumference in intervention group. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 35. Valdez A, Banerjee K, Ackerson L, Fernandez M. A multimedia breast cancer education intervention for low-income Latinas. *Journal of Community Health* 2002;27:33-51. [Overview, Applicability] | 1,197 low-income, low-education Latinas recruited from three community health clinics, two medical centers, and one community-based organization | Cancer: clinic-based touch screen computers in free-standing kiosks | Multimedia Breast Cancer Educational Kiosk: a multimedia tool designed to teach low-income, low-education Latinas about breast cancer screening. It contains 10 modules about breast cancer, including risk, early detection, screening concerns, mammogram, breast self-exam, options for those without insurance, etc. Multimedia format includes video, animation, stills, music, and narrative. | Control group: recorded baseline data and then used program. Intervention group: used program and then completed study measures. | Knowledge, attitude, intent | Effective in increasing knowledge about breast cancer and the likelihood of asking their doctors about mammograms. Greatest knowledge differences seen in those who had not had mammography before. No significant effects on attitude because most were favorable before the intervention. Greater intention to ask a doctor about getting a mammogram in intervention group, with greater difference in women who had never had a mammogram or had not had a recent mammogram, and with 8 years of education. |
| 36. Walther J, Wang Z, Loh T. The effect of top-level domains and advertisements on health Web-site credibility. *Journal of Medical Internet Research* 2004;6:e24. [Appropriateness] | 111 participants recruited through intercept in shopping mall (median age 32, 53% female), 45 recruited through snowball sampling (median age 50, 68% female) | Health information: lab computer with Internet | Mock-ups of Web sites | Respondents examined 1 of 12 randomly assigned Web site mock-ups that varied in either topic area, domain name, or presence of advertising. Then they completed credibility survey. | Credibility | Interaction effects: found a trend for advertisements having deleterious effects on the credibility of sites with .org domain, but positive effects on sites with .com or .edu domains. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 37. Winzelberg AJ, Classen C, Alpers GW, Roberts H, Koopman C, Adams RE, et al. Evaluation of an Internet support group for women with primary breast cancer. *Cancer* 2003;97:1164-73. [Applicability] | 72 women with breast cancer, recruited from ads on radio and in newspapers, and flyers distributed to oncology offices in California.<br>80% Caucasian, 4% African American,<br>4% Asian, 6% Hispanic/Latino, 6% other.<br>64% college graduates or higher, 28% some college.<br>If they did not have a computer, they were loaned a Web-TV for the study. | Cancer: home computer with Internet or Web-TV | Bosom Buddies: a structured facilitated support group. New topic each week, moderator facilitated discussion on the topic and related concerns; could also read survivor stories, share their own experiences, keep a Web journal, group format asynchronous | Control group: wait-list control. Intervention group: used Bosom Buddies | Depression, stress, coping and adjustment to cancer, group experience, usage | Participants logged onto site mean of 34 times, posted an average of 36 support messages. Personal journal was not used regularly. Improvements in intervention group in depression, stress, and cancer-related trauma measures. No change in anxiety or coping. Intervention group participants reported that they used the group to provide/receive support, form new friendships, understand that their problems were not unique, and to confront difficult problems and fears. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 38. Womble LG, Wadden TA, McGuckin BG, Sargent SL, Rothman RA, Krauthamer-Ewing ES. A randomized controlled trial of a commercial Internet weight loss program. *Obesity Research* 2004;12:1011-8. [Applicability] | 47 women with mean age 43.7 | Weight loss: home computer with Internet | e-Diets.com: a commercial Internet site in which membership allows user access to a virtual visit with a dietitian; a diet that is matched to needs, likes, and lifestyles; meal plans and grocery lists; social support; message boards; animated fitness instructor; 24-hour help desk; e-mail reminders; e-mail newsletter; buddy program | Control group: received weight loss manuals, LEARN program for weight management, and weight maintenance survival guide.<br>Intervention group: used e-Diets.com.<br>Both groups received 11 brief clinic visits to obtain weight and blood pressure measures. | Body weight, eating habits, depression and quality of life, physiological measures | Participants in e-Diets lost significantly less weight at week 16 and week 52 than those who used manual when last measurement was used for drop-outs. (When baseline measures were used for drop-outs for analysis, results were not significant.) Those who attended more clinic visits in either group lost more weight. Those who used food diaries in either group lost more weight. Participants who logged onto e-Diets more, lost more weight as compared to the weight gain in those who logged on less frequently. No differences between groups in eating behaviors or quality-of-life measures. Both groups reported increased cognitive restraint; improvements in physical function and vitality; and decreased depression, dietary disinhibition, and hunger. No differences in blood pressure, glucose, and lipids at 52 weeks. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| **Quasi-Experimental Designs** | | | | | | |
| 39. Baranowski T, Baranowski J, Cullen KW, Marsh T, Islam N, Zakeri I, et al. Squire's Quest! Dietary outcome evaluation of a multimedia game. *American Journal of Preventive Medicine* 2003;24:52-61. [Overview, Applicability] | 1578 children—fourth grade students; 690 Caucasian, 268 African American, 476 Hispanic, 105 other; 736 boys, 803 girls | Nutrition: school-based computer with CD-ROM | Squire's Quest: a 10-session, interactive multimedia game that allows user to engage in challenges requiring skills and goals related to increasing fruit and vegetable consumption | Control group: nutrition education as usual. Intervention group: interacted with the game for 10 sessions over 5 weeks. | Fruit, 100% juice, and vegetable consumption | Intervention group increased by one serving per day, but not enough to meet five per day requirements. |
| 40. DiNoia J, Schinke SP, Pena JB, Schwinn TM. Evaluation of a brief computer-mediated intervention to reduce HIV risk among early adolescent females. *Journal of Adolescent Health* 2004;35:62-4. [Applicability] | 205 early adolescent females age 11-14. Recruited from social services agencies in New York State. 43% black, 46% Hispanic, 11% white; mean age 13.1 | HIV/AIDS prevention: clinic-based computer with CD-ROM | Keeping It Safe: program uses didactic information along with an interactive game to reinforce the information and a video of woman who contracted HIV as an adolescent who discusses prevention, attitudes, etc. Shown epidemiological data related to incidence and prevalence among young women; interact with scenarios and simulations to learn a four-step model of assertive responding | Control group: wait-list control. Intervention group: interacted with Keeping It Safe. | AIDS knowledge, protective attitudes (peer norms, partner norms, attitudes toward sexually active youth), risk reduction self-efficacy | Those in the intervention group had higher posttest knowledge and self-efficacy than the controls. Within-group analyses showed that intervention group showed improvements in knowledge and peer norms with trend toward improvement in partner norms, attitudes, and self-efficacy, while control group self-efficacy significantly decreased. |
| 41. Duncan TE, Duncan SC, Beauchamp N, Wells J, Ary DV. Development and evaluation of an interactive CD-ROM refusal skills program to prevent youth substance use: "refuse to use." *Journal of Behavioral Medicine* 2000;23:59-72. [Appropriateness, Applicability] | 74 high school students; 61% male, 39% female; mean age 15.2 | Substance abuse prevention: school-based computer with CD-ROM | Refuse to Use Program: designed to provide socially acceptable refusal skills needed to deal with offers of marijuana. Includes six refusal skill vignettes | Control group: no treatment. Intervention group: used computer-based intervention as a group in a classroom setting. | Self-efficacy for marijuana refusal, intention, social norms, recall of refusal strategies | Intervention group showed greater refusal self-efficacy, greater intent to refuse. Intervention group more likely to agree that pressuring someone who says no is not good (social norms) and recalled 50% of the strategies. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 42. Frenn M, Malin S, Bansal N, Delgado M, Greer Y, Havice M, et al. Addressing health disparities in middle school students' nutrition and exercise. *Journal of Community Health Nursing* 2003;20:1-14. [Acceptability, Applicability, Key Findings] | 130 urban low- to middle-income middle school students; 58 African American, 47 Caucasian, 4 Hispanic, 9 Asian, 4 Native American | Nutrition and physical activity: school-based computer with CD-ROM | Internet and video sessions for those in precontemplation and contemplation focused on raising awareness of current eating and exercise, identifying benefits, and overcoming barriers to consuming low-fat diets and exercise. Those in preparation, action, and maintenance were trained as "peer models" and co-led healthy labs. All students received online feedback. | Control group: traditional classroom sessions. Four-session Internet and video intervention with snack lab and, in one school, a gym lab | Access to low-fat foods and physical activity, food habits, physical activity log, level of participation | Fat in diet decreased with each Internet session in which students participated. Effects of the intervention varied by gender and race. Percentage of fat reduced significantly (p=.018) for black, white, and black/Native American, and Hispanic girls (but not Asian) in intervention group. Boys in the control group decreased fat more than boys in intervention group, but most of the intervention boys reported less access to low-fat foods. Intervention group boys increased physical activity for all races except Native American. No difference by sex for physical activity. No effect of peer-led food lab. Students with gym lab and Internet increased physical activity. Internet and control had decrease in exercise with less decrease in intervention than control group. *HP2010* goal of 30% or less calories from fat was not reached. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 43. Hornung RL, Lennon PA, Garrett JM, DeVellis RG, Weinberg PD, Strecher VJ. Interactive computer technology for skin cancer prevention targeting children. *American Journal of Preventive Medicine* 2000;18:69-76. [Applicability] | 192 elementary school students (98% third and fourth grade); 44% girls, 56% boys | Cancer: school-based computer with CD-ROM | CD-ROM using animated cartoon characters and video clips of a dermatologist providing information; interactivity involved choosing which segments to view in which order. | Randomized by classrooms into three groups: no-treatment control, computer intervention, and standard didactic. | Knowledge about the sun, attitudes re tanning, behavioral practices | Significant changes in knowledge for CD-ROM group as compared to both groups at posttest and followup. Significant differences in attitude for CD-ROM group as compared to the other groups at posttest, but the difference between computer group and standard group no longer significant at followup. No differences on behavior measures at either point. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 44. Houston TK, Cooper LA, Ford DE. Internet support groups for depression: a 1-year prospective cohort study. *American Journal of Psychiatry* 2002;159:2062-8. [Applicability] | 103 adults recruited from online depression support groups and message boards. 79% female, 42% unemployed, 82% at least some college, 101 formally diagnosed with depression | Depression: home computer with Internet | Internet support groups available in the public domain | Identified cohort group from online sites, administered baseline and followup surveys at 6 months and 12 months. Additionally, compared findings to participants in another large study of depression. | Depression, social support | Over one-half reported more than 5 hours of Internet depression support group use in the prior 2 weeks. 95% agreed that chatting on the Internet helped their symptoms; one-third preferred online support, 81% still received face-to-face treatment; 72% reported their providers knew of their online support. At 1-year followup, 72.6% still participating in the groups. 78.8% still receiving traditional treatment as well. 62% said online experience influenced them to ask their provider a question, and 26% had influenced them to make a change in medications. This cohort had lower levels of tangible, emotional, affectionate support and positive social interactions compared with participants from another large depression study. Social support scores did not change over time between more frequent users of the Internet support groups, indicating that face-to-face support did not decline over time. Depression resolved in 42.9% of frequent users compared to 20.7% of less frequent users. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 45. Jantz C, Anderson J, Gould SM. Using computer-based assessments to evaluate interactive multimedia nutrition education among low-income predominantly Hispanic participants. *Journal of Nutrition Education and Behavior* 2002;34:252-60. [Appropriateness, Applicability, Key Findings] | 70 adults recruited from nutrition, health, and ESL programs in Colorado; "primarily Hispanic and low income (<$15,000 per year)" | Nutrition: clinic-based computer with interactive multimedia program | Make a Great Start: one of six modules in the La Cocina Saludable Interactive Multimedia (IMM) program, which targets Hispanic adults. This module provides knowledge about the importance of breakfast, includes information about benefits and barriers, emotional arousal/dramatic relief by emphasizing family, self-efficacy by including practice activities. | Control group: interacted with computer program about budgeting. Intervention group: interacted with computer program about importance of breakfast. | Knowledge, attitude, stage of change | Intervention group significantly increased knowledge and attitudes. No real change in stage of change due to short nature of intervention. Use of IMM was faster than actual educator delivering same materials. |

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| **Single Group Designs** | | | | | | |
| 46. Barnes MD, Penrod C, Neiger BB, Merrill RM, Thackeray R, Eggett DL, et al. Measuring the relevance of evaluation criteria among health information seekers on the Internet. *Journal of Health Psychology* 2003;8:71-82. [Appropriateness] | 578 adults who were employees of Idaho National Engineering and Environmental Labs who were enrolled in the Occupational Medicine Health Promotion Program; 57% male, 84% attended at least some college | Health information: lab computer with Internet | Three publicly available Web sites about cold and flu information | Participants first ranked 12 criteria in importance for evaluating health information. Then they used those criteria to evaluate three preselected Web sites that had been chosen on the basis of low, medium, and high quality. | Ranking of the criteria, rating of the Web sites | Participants ranked criteria related to credibility of information and reliability of source as most important with design and aesthetics seen as least important. When rating actual Web sites, six criteria proved to be significant predictors of quality: content, design and aesthetics, currency of information, intended audience, contact addresses, and user support. Those younger than age 50 were better able to select the high-quality site. |
| 47. Beebe TJ, Asche SE, Harrison PA, Quinlan KB. Heightened vulnerability and increased risk-taking among adolescent chat room users: results from a statewide school survey. *Journal of Adolescent Health* 2004;35:116-23. [Applicability] | 40,376 ninth grade students who had Internet at home, of which 19,511 reported accessing chat rooms | Social support: home computer with Internet | World Wide Web | Data from the Minnesota Student Survey were analyzed to determine demographic, psychological, environmental, and behavioral differences between chat room users versus nonusers. | Psychological, environmental, and behavioral factors; Internet activities | Chat room use was consistently, positively, and significantly associated with adverse psychological and environmental facts and engagement in risk behaviors among ninth grade boys and girls. Other Internet activities, such as use of e-mail or games, did not show a consistent pattern of positive associations with these factors. Cannot infer causality: possible that teens who need support are trying to attain it via the chat rooms. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 48. Birru MS, Monaco VM, Lonelyss C, Drew H, Njie V, Bierria T, et al. Internet usage by low-literacy adults seeking health information: an observational analysis. *Journal of Medical Internet Research* 2004;6: e25. [Appropriateness] | Eight adults with low literacy; mean age 41.5; seven African American, one Asian | Health information: lab computer with Internet | World Wide Web | All participants had a computer skills session. Then participants were asked to use Internet and Google to research information on three health-related questions, using a think-aloud protocol. Then they were asked to navigate a specific Web site. | Search engine usage, ability to answer questions, information accessed, attitudes | Most found generating search terms challenging, difficulty remembering to space between words, some difficulty with spelling; generally retained navigational skills learned in skills session; difficulty generating independent queries and answering specific questions. Participants at times able to locate answers, but could not put into their own words, thus suggesting comprehension difficulties. Average reading level of sites accessed was 10th grade. Seven of eight accessed sponsored sites. All were at least moderately comfortable with their searching experience. Seven of eight felt it was easy to locate trustworthy information. All were enthusiastic about improving skills and using computers. |
| 49. Block G, Miller M, Harnack L, Kayman S, Mandel S, Cristofar S. An interactive CD-ROM for nutrition screening and counseling. *American Journal of Public Health* 2000;90:781-5. [Acceptability] | 281 adults | Nutrition: clinic-based computer with CD-ROM | Interactive program designed to assess fat and fiber intake; compare to recommendations; and provide tailored information to intake, stage of change, and lifestyle habits | Users interacted with the program, then completed questionnaire, followup phone calls made 2 to 4 weeks later. | Satisfaction, new learning, goal setting, and attainment | Large majority found the program easy to use, would recommend it to a friend, thought it could be longer; 78% reported learning something new. 60% had selected a personal goal. Of those who could be reached for followup, 50% tried to reach their goal. |

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| 50. Bowen DJ, Ludwig A, Bush N, Meischke J, Wooldridge JA, Robbins R. Early experience with a Web-based intervention to inform risk of breast cancer. *Journal of Health Psychology* 2003;8:175-86. [Acceptability] | Study 1: Utilization: 268 women; 88% white, 56% college degree. Study 2: Interviews with nonusers: 83 women | Cancer: home computer with Internet | WIRES: a multicomponent Web site that includes information tailored to personal risk, exercise, eating habits, mammogram history, and age. Components include information, interactive features (“make a commitment” quizzes), contact with study staff, discussion forums. | This study included an analysis of usage by those who actually used the Web site along with identification of predictors or usage, and interviews with nonusers. | Quality of life, healthcare coverage, risk factors for breast cancer, perceived risk, usage patterns | Usage: by week 3, only 21.5% of users had logged into the Web site. After a cue at 3 weeks, usage increased to 37.2%. By 3 months, 47.6% had logged into the Web site. An additional cue at 3 months increased usage by 3.4%. By 6 months, usage was 58.7%. Average length of visit was 30 minutes. Most frequently used pages were home page, personal risk information, exercise and healthy eating pages, then pages on breast cancer, risk factors, and Tamoxifen use. Main reason for not logging in was being too busy. Most difficult part of getting online was finding time. Women with higher incomes and employed full time were less likely to use Web site. Women with higher mental health scores were more likely to use the Web site. Those with lower perceptions of their general current health were less likely to use the Web site. Those with higher perceptions of risk were more likely to use Web site. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 51. Cimino JJ, Li J, Mendonca EA, Sengupta S, Patel VL, Kushniruk AW. An evaluation of patient access to their electronic medical records via the WWW. *Proceedings of the American Medical Informatics Association Symposium* 2000:151-5. [Acceptability] | Eight adults recruited from private practices of internists at NY Presbyterian Hospital. Only five were actual users; the others did not participate after consent. | Patient-provider interaction: home computer with Internet | PatCIS gives patients access to their electronic medical record, allowing them to add data, review online health information, and apply their own clinical data to guideline programs that offer health advice. System supports security functions and records user activities. User functions: data entry data review, education, advice, comments, and help. | Review of system usage logs—sessions were analyzed by the success of the login, number of functions used during the sessions, duration of the sessions, and whether the user logged out. | User logs | Logged in 243 times, 33 logins failed due to incorrect password or code, 14 sessions had OK login but no other activity. No illegal logins. 196 logins used one or more functions. Log out used 122 times, not 74 times. Most frequently used function: checking lab data 140 times (71%), reports 40 times. Data entry functions: vitals entered 31 times, diabetes information 14 times. Educational functions (links) used 35 times, advice functions 6 times. No adverse reports received from physicians. |
| 52. Colvin J, Chenoweth L, Bold M, Harding C. Caregivers of older adults: advantages and disadvantages of Internet-based social support. *Family Relations* 2004;53:49-57. [Acceptability] | 63 caregivers recruited from 15 Web sites; 89% women, mean age 54.9 years; 59% not employed outside the home; spent 88 hours/week caregiving; 12.6 hours on Internet | Social support for caregivers: home computer with Internet | Web sites offering social networks | Surveyed caregivers of older adults who used Internet support groups. | Advantages and disadvantages of online social support | Advantages cited: anonymity and nonjudgmental atmosphere; asynchrony; able to personalize use of computer-mediated communication (can lurk if desired and delete content); allows expansion of network. Disadvantages: absence of physical presence, social cues; desire for more intimacy; desire to give/receive tangible support; anonymity (not being sure if people are really who they say they are); technical problems; loss of anonymity so they screen what they say; online cliques. Disadvantages cited by small numbers, 24% did not cite any, five left blank. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 53. Czaja SJ, Rubert, MP. Telecommunications technology as an aid to family caregivers of persons with dementia. *Psychosomatic Medicine* 2002;64:469-76. [Acceptability] | 44 caregivers of family members with dementia: 21 Cuban American, 23 white; 34 female; mean age 67.5; 62% with income <30,000; 41% high school or less | Social support for caregivers: home computer-integrated telephone system | CTIS is an information-network that uses computer-telephone technology. It uses screen phones and allows both text and voice messages. Phone system allows users to conference call, join phone support group, leave/send messages to family and care providers; provides caregiver resources, respite functions for patients. | Participants used telephone system for 6 months, then completed survey. | Usability, satisfaction | Generally, participants liked the system and found it easy to use. System use averaged 49 calls/caregiver. Most used function was calling family members. 80% participated in the discussion group. 82% of those liked participating in the discussion groups, and 86% found participation valuable. Several caregivers could participate who could not get to face-to-face support groups. |
| 54. Davis JJ. Disenfranchising the disabled: the inaccessibility of Internet-based health information. *Journal of Health Communication* 2002;7:355-67. [Access] | NA | Health information: lab computer with Internet | Web sites about health and illness | 500 Web sites representing common illnesses/ conditions were evaluated for accessibility for visually impaired users who use automated screen readers. | Accessibility | Only 19% of sites were found to be accessible. 64.7% failed because of inability to satisfy a single Priority 1 criteria as specified by the Web Accessibility Initiative of the World Wide Web Consortium. Most failed to provide text descriptions of graphic elements or provided inadequate descriptions. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 55. Epstein YM, Rosenberg HS, Grant TV, Hemenway N. Use of the Internet as the only outlet for talking about infertility. *Fertility and Sterility* 2002;78:507-14. [Applicability] | 589 adults; 99.1% female, >85% at least some college education | Infertility: home computer with Internet | Web site for the International Council on Infertility Information Dissemination | Survey was completed by visitors to the Web site. Researchers then compared two groups: those whose only support was online (OO) and those with additional support (AO). | Diagnostic and treatment information; medication usage; current treatment status; Internet activity; perceived consequences of Internet activity; self-assessment of ways of dealing with infertility; current social and emotional well-being; depression | Greater proportion of OO than AO are not college educated, have no health insurance coverage for infertility, and have a lower household income. OOs spend more hours/day on the Internet for any activity and infertility-related activity; 1/5 of each group are lurkers. Both groups report that their participation has had important cognitive, behavioral, and relationship consequences (switching to a specialist, learning how to deal with doctors, decreasing communication about infertility with partner [OO more than AO]). OOs are more depressed, consider infertility more stressful, report poorer coping strategies for dealing with infertility, worry more, are less satisfied with important relationships, perceive that they receive less support. Lower income predicted greater depression. Time spent on Internet did not predict depression. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 56. Erwin BA, Turk DL, Heimberg RG, Fresco DM, Hantula DA. The Internet. Home to a severe population of individuals with social anxiety disorder? *Journal of Anxiety Disorders* 2004;18:629-46. [Applicability] | 434 participants recruited from Internet sites on social anxiety; 291 women, 140 men, 3 no response; also 229 who sought face-to-face treatment and 36 controls without psychological distress | Anxiety: home computer with Internet | World Wide Web | Surveyed Internet users with social anxiety disorders, those who sought face-to-face treatment, and controls. | Internet use, clinical and impairment variables | Internet survey respondents reported greater severity of and impairment due to social anxiety disorder than treatment-seeking sample. They reported positive (more social support, developing increased confidence) and negative effects of Internet use (fewer face-to-face social bonds, more comfortable interacting on Internet than in person). |
| 57. Escoffery C, McCormick L, Bateman K. Development and process evaluation of a Web-based smoking cessation program for college smokers: innovative tool for education. *Patient Education and Counseling* 2004;53:217-25. [Acceptability] | 35 college students from one campus; 20 women, 15 men | Smoking cessation: home computer with Internet | Kick It!: a four-session program of smoking cessation information, support (ask an expert, message boards, personal stories). Information tailored by stage of change. Each available for 2 weeks. | Users interacted with site, then completed surveys or were interviewed. | Process information, quit rate | 14.3% (5) participants quit at end of intervention; at 6-month followup, 25.7% quit. Quit rates of this program were as good as and better than other reports of face-to-face and online interventions. Users rated reading the text, taking quizzes, and using the links as the top activities. Limited use of ask-the-expert and message boards. Participants found the program somewhat useful, interesting, valuable, and personally relevant. Many found it easy to use. Log files and usage self-report showed 82.4% agreement, with some users reporting attending one more session than logs indicated. Interviews also yielded mostly positive feedback. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 58. Eysenbach G, Kohler C. How do consumers search for and appraise health information on the World Wide Web? Qualitative study using focus groups, usability tests, and in-depth interviews. *British Medical Journal* 2002;324:573-7. [Availability, Appropriateness] | 21 adults in focus groups (5 men, 16 women; mean age 37); 17 adults in usability study and interviews (6 men, 11 women; mean age 38) | Health information: lab computer with Internet | World Wide Web | Focus groups, usability study in which participants used the Internet to find answers to specific researcher-generated health questions and individual interviews | Self-report and performance of how they search for health information and determine its credibility | Users reported that Web sites from official authorities, with professional layout, understandable and professional writing, and citation of scientific references, were the most often mentioned criteria. Observation showed all users started with search engine, most used suboptimal search strategy; usually chose one of first displayed results. Users could answer all but 7 of the 136 total questions, but quality of answers was not assessed. Also, users did not attend to the source of the information while searching. |
| 59. Fallows D. Search engine users: Internet searchers are confident, satisfied and trusting—but they are also unaware and naive. Pew Internet & American Life Project, 2005. Available online at *www.pewinternet.org./PPF/r/146/report_display*. [Availability] | 1,399 adult Internet users | Health information: home computer with Internet | NA | Survey of Internet users | Search engine use and satisfaction | 84% of Internet users have used search engines, 92% who use search engines are confident, and 87% report successful search experiences most of the time. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 60. Goldsmith DM, Silverman LB, Safran C. Pediatric Cancer CareLink—supporting home management of childhood leukemia. *Proceedings of the American Medical Informatics Association Symposium* 2002:290-4. [Availability] | 25 parents, all with greater than high school education, 92% had home computers with Internet; 34 clinicians | Cancer: home computer | NA | Formative interviews to determine parents' and clinicians' information needs and interest in computer-based tool | Help needed, satisfaction with providers, current communication | Parents report need for help with medication management, less than satisfied with help from providers, currently communicate with providers via telephone; 38% said they used Internet weekly to find information. Clinicians report decision support, prescription refill support, and education support would be important to include for home management tool and concern about impact on workflow. |
| 61. Han HR, Belcher AE. Computer-mediated support group use among parents of children with cancer—an exploratory study. *Computers in Nursing* 2001;19:27-33. [Acceptability] | 73 parents; mean age 38, 75% women, 89% white, >80% at least some college | Cancer: home computer with Internet | Three online support groups for family members of children with cancer. Groups were part of more than 70 groups hosted by Association of Cancer Online Resources (ACOR) | Parents were recruited from online support groups and surveyed about their support group use. | Use of computer for support | Advantages cited by parents: getting information, sharing experiences, general support, venting of feelings, accessibility, and use of text. Disadvantages: noise, negative emotions, large volume of mail, lack of physical contact. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 62. Hassol A, Walker JM, Kidder D, Rokita K, Young D, Pierdon S, et al. Patient experiences and attitudes about access to a patient electronic healthcare record and linked Web messaging. *Journal of the American Medical Informatics Association* 2004;11:505-13. [Acceptability] | 1,421 adults recruited from a medical practice, needed own computer; 60% female, 78% between the ages of 31-64, more than 25% had 4-year degree, almost all were non-Hispanic whites | Patient-provider interaction/ electronic medical record; home computer with Internet | MyChart is a new feature in the electronic health record (EHR) in use throughout the Geisinger Health system. This allows patients to view selected portions of their EHR and exchange electronic messages with their doctor's practice. Application is Web-based, password protected, encrypted. Patients can view 25 lab tests; review allergies, medications, and problem lists; view past and future office visits; review health history; send messages and queries to providers; and request an appointment, prescription renewals, and referrals. | Survey of MyChart users with focus groups conducted to supplement survey findings, interviews with physicians | Ease of use, completeness and accuracy of information | Users had little difficulty using the system even among adults whose education was high school or less. Patients very satisfied with system. 65% rated their information as complete, and 75% rated medical history as accurate. Most patients were not concerned about security/ privacy of their medical information or about learning of test results before discussing them with their providers. Patients least preferred written or telephone communication and had higher preference for in-person and online communication (especially for prescription renewals, general medical questions). MDs preferred in-person and telephone communication. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 63. Kaufman DR, Starren J, Patel VL, Morin PC, Hilliman C, Pevzner J, et al. A cognitive framework for understanding barriers to the productive use of a diabetes home telemedicine system. *Proceedings of the American Medical Informatics Association Symposium* 2003:356-60. [Overview, Access, Acceptability] | 25 elderly diabetic Medicare patients living in rural Upstate New York (mean age=73, mean educational level 12.1 years, 45% had Internet experience, 100% English speaking) and New York City (mean age=69.6, mean educational level 8.6 years, 36% had Internet experience, 86% Spanish speaking) | Diabetes: home telemedicine system | IdeaTel: a home telemedicine-synchronous video-conferencing, electronic transmission of fingerstick glucose and blood pressure readings, e-mail to a physician and nurse case manager, review of clinical data, access to Web-based educational materials in English and Spanish | Usability testing included a cognitive walkthrough analysis to characterize task complexity and identify potential problems. Also included a field usability testing in patients' homes during which patients interacted with the equipment and performed specified functions. | Cognitive walkthrough, observation | Cognitive walkthrough highlighted areas of complexity. Usability testing showed difficulty using the mouse; all of the novice users had difficulty developing a mental model of the system, thereby making navigation difficult, impact of health literacy (e.g., users had difficulty reading/interpreting tables, understanding charts, recognizing abnormal values). |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 64. Kusec S, Brborovic O, Schillinger D. Diabetes Websites accredited by the Health on the Net Foundation Code of Conduct: readable or not? *Studies in Health Technology and Informatics* 2003;95:655-60. [Appropriateness] | NA | Diabetes: lab computer with Internet | Diabetes Web sites | Using the HONcodeHUNT search engine, 99 Web sites on diabetes were identified for evaluation. 100-200 words of text were then copied and pasted into Microsoft Word, where the Flesch Reading Ease (FRE) and Flesch-Kincaid evaluations were used to determine readability. | Readability | Mean FRE score of 41.7 corresponding to “difficult” reading ease. Mean Flesch-Kincaid score of 10.8th grade level. Reading level of average U.S. adult is 8th grade. 86.9% of reviewed Web sites would be too difficult for the average adult. |
| 65. Lenert L, Cher D. Use of meta-analytic results to facilitate shared decision-making. *Journal of the American Medical Informatics Association* 1999;6:412-19. [Overview, Acceptability] | 191 patients with benign prostatic hypertrophy (BPH) recruited over Internet; 81% had at least some college, 71% had e-mail addresses | Benign prostatic hypertrophy: home or clinic computer with Internet | Internet site that measures current symptoms and desired level of symptom reduction, describes alternative treatments for BPH and potential effects of alpha blocker terazosin, computes and displays the probability of user achieving objective of symptom reduction by using terazosin or placebo | Users interact with site, then complete online questionnaire. | Perceived usefulness of information | 93% found the information useful; 71% believed this type of information should be discussed before prescribing medications. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 66. Lieberman MA, Golant M, Giese-Davis J, Winzlenberg A, Benjamin H, Humphreys K, et al. Electronic support groups for breast carcinoma: a clinical trial of effectiveness. *Cancer* 2003;97:920-5. [Acceptability] | 32 women with breast carcinoma (CA), recruited from Web sites related to breast CA and physicians' offices, hospitals, community centers. 82% between 40-60, 67% married, 70% had at least some college | Cancer: home computer with Internet | Closed electronic support group. Users also had access to private newsgroup in which they could post pictures, share their cancer stories, and chat. | Four groups of eight participants, met for 1.5 hours/week for 16 sessions. Groups were therapist-led, but group determined discussion. | Depression, pain, posttraumatic growth | Technical problems: provider "timed them out" during a session. Significant reductions in depression, reactions to pain. Positive trend posttraumatic growth, expressing somewhat more zest for life. 67% found group beneficial. Those who withdrew from study had lower scores in ability to contain anxiety, more likely to suppress their thoughts and feelings regarding their illness. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
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| 67. Liederman EM, Morefield CS. Web-messaging: a new tool for patient-physician communication. *Journal of the American Medical Informatics Association* 2003;10:260-70. [Acceptability] | 238 patients from University of California Davis Primary Care Network. Also eight clinicians, nine medical assistants, four office staff | Patient-provider interaction: home computer with Internet | RelayHealth system provides Web-based communication services that are secure and clinically structured. Offers messaging, non-urgent asynchronous consults, appointments, medication refills, and preventive care reminders. Can be used by doctor, authorized staff, and patients with login and password. | Survey of RelayHealth system participants on use of Web-messaging system | Usability, satisfaction | Only 3% had never used system, 49.6% once or twice, 26% three to four times, 21% five or more times. 66.4% found system very easy, 22.4% easy, 3% found it somewhat difficult, and one respondent found it very difficult, 61.2% very satisfied, 24.6 satisfied, 6% somewhat or very dissatisfied (related to lack of or slow response from clinic). All who received a timely response were very satisfied. 78% rated Web messaging better or much better than calling their doctor, 78% said access to provider was better/much better with electronic communication. Three reasons patients used phone included (1) when electronic method was not yet in place; (2) they wanted quicker answers; or (3) it was easier to explain the problem over the phone. Patients' suggestions for improvement include quicker response times and adding additional features to the site such as lab results and medical records access. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 68. Masys D, Baker D, Butros A, Cowles KE. Giving patients access to their medical records via the Internet: the PCASSO experience. *Journal of the American Medical Informatics Association* 2002;9:181-91. [Acceptability, Applicability] | 41 patients enrolled (needed to have own computer and Internet). Typical patient enrollee was female (73%), well educated (71% with college degree), excellent computer skills (49%), and excellent Internet knowledge; 68 physicians | Electronic medical record: home computer with Internet | Patient-Centered Access to Secure Systems Online (PCASSO): a secure system allowing patients to view their medical records online. Requires a multistep procedure for secure login. | Monitored usage data and also surveyed users. | Usability, satisfaction | No penetration of system by intruders during 12-month period. 88% of those patients providing feedback reported the multistep secure login to be reasonable or very reasonable. 60% of doctors found it reasonable, but 40% found it unreasonable or intolerable. Majority of both groups rated having electronic access to medical records very highly. Both groups were satisfied with the security safeguards. Large majority of both groups felt there was very high value in having access to records via the Internet. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 69. Preece J, Nennecke B, Andrews, D. The top five reasons for lurking: improving community experiences for everyone. *Computers and Human Behavior* 2004;20:201-23. [Acceptability] | 1,188 survey responders, of whom 219 were lurkers; 79% had at least some college, 56.3% women | Social support: home computer with Internet | MSN bulletin board communities | Survey posted to a random sample of MSN bulletin board communities. Total of 375 communities selected. Lurkers' responses were compared to posters' responses. | Attitudes toward posting | No difference between lurkers and posters based on demographics. Found that both groups go online looking for information. Lurkers less enthusiastic about community membership, posters have a greater sense of belonging and satisfaction with the community. Lurkers state they do not post because just reading is enough, still learning about the group/shy, being helpful by not posting if nothing new to offer, nothing to offer, no requirement to post, want to remain anonymous, could not make the software work to be able to post. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 70. Radvan D, Wiggers J, Hazell T. HEALTH C.H.I.P.S.: opportunistic community use of computerized health information programs. *Health Education Research* 2004;19:581-90. [Overview, Access] | Study 1: 386 people age 18-83, mean age 42.9; 70.2% female. Study 2: 55.3% male, age range of users from <12 to >60 with the greatest proportion (31.4%) of users children under age 12 | Health information: community-based touch screen computer in free-standing kiosks | HEALTH CHIPS (Computerized Health Information Programs): health education modules (smoking, blood pressure, cervical cancer) available on a touch-screen computer kiosk. Modules include information, personal risk assessment with tailored feedback, and quizzes. Modules also include text, photos, diagrams, animations, sound, and video. | 1. Intercept: a kiosk loaded with three modules (blood pressure, cervical cancer, and smoking) was in a shopping center for 7 months. Then, trained interviewers approached subjects every 15 minutes for intercept-interviews. Utilization study: kiosks established at 17 venues over 12 months with 17 modules on many health topics. Program database collected usage data. | 1. Intercept: exposure, attention, and use; usefulness and information; barriers to use<br>2. Utilization | 1. Intercept: a total of 99.7% of participants were in the vicinity of the kiosk (exposure); 77.4% of these noticed it, and 20.8% of these used it. Program acceptability was high. Most common barriers to use were time constraints, disinterest, kiosk already in use, not comfortable using kiosk in public. 2. Utilization: there were 57,064 uses in 2,943 days (19.4 uses per kiosk per day). Most used the following topics: sexual health, smoking, and drunk driving. Most often submodules used were quizzes and self-assessments. Also had a comparison of use across different community settings. |
| 71. Reeves, PM. Coping in cyberspace: the impact of Internet use on the ability of HIV-positive individuals to deal with their illness. *Journal of Health Communication* 2000;5(Suppl):47-59. [Acceptability] | 10 adults with HIV; 60% male, 80% Caucasian, all at least with some college | HIV: home computer with Internet | NA | Semi-structured interviews about Internet use and coping | History of Internet use, how they use the Internet, and coping strategies | Internet use promotes empowerment, augments social support, and facilitates helping others. |
| 72. Rozmovits L, Ziebland S. What do patients with prostate or breast cancer want from an Internet site? A qualitative study of information needs. *Patient Education and Counseling* 2004;53:57-64. [Availability, Appropriateness] | 28 adults with breast or prostate cancer for focus groups; 8 adults with breast or prostate cancer for individual interviews | Cancer: home computer with Internet | DIPEx Web site: presents video, audio, and written clips from interview studies with people about their experiences of health and illness. Modules available for breast and prostate cancer; hypertension; and cancer of the testis, cervix, and bowel. | Interviews and focus groups with members of the target audience | Information needs, sources of information, review of Web site content | Cancer patients have information needs that change over time, and some information needs are unmet. Sample seems aware of issues with getting information from the Internet. Interviewees liked DIPEx site, but site could be improved to provide other needed information, such as financial help and benefits, practical advice, non-Internet resources. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 73. Ryan R, Kobb R, Hilsen P. Making the right connection: matching patients to technology. *Telemedicine Journal and e-Health* 2003;9:81-8. [Overview, Access, Acceptability] | 911 veterans with chronic medical or mental health problems | Patient-provider interaction: home with traditional telehealth technology; Web-based messaging devices; disease management tool; cameras, PC with Internet for supervised chat rooms | See technology column. | Developed an algorithm to match patients to technology based on education, vision, manual dexterity, willingness to use technology, and compliance to medical regimen. | Satisfaction, ease of use, self-reported functional status (physical function, bodily pain, general health, vitality, mental health, and role function) | 94% satisfied with their primary technology device at 12 months; 93% found the technology easy to understand, 95% easy to use, 87% device generally reliable; 90% felt the Community Care Coordination Service program helped educate them about their chronic disease, 88% helped them manage their health better; 82% improved communication with providers, 95% would recommend participation to other veterans. Initial medication compliance at 63%, increased to over 93% during the study. Self-reported functional status either improved or remained unchanged for all but one parameter (physical function). |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 74. Shaw BR, McTavish F, Hawkins R, Gustafson DH, Pingree S. Experiences of women with breast cancer: exchanging social support over the CHESS computer network. *Journal of Health Communication* 2000;5:135-59. [Acceptability] | 12 women participating in the Comprehensive Health Enhancement Support System (CHESS).<br>Mean age 51, all at least high school educated, one-half college educated | Cancer: home computer connected to central server | CHESS: contains 11 tools that provide information, decisionmaking, and support services. | Women with breast cancer who used CHESS were interviewed to examine the experience of giving and receiving support in a computer-mediated environment. | How they used CHESS, how do CHESS support groups compare with other support groups, how could CHESS work better | Some findings include: equalized participation important; no social cues to bias. Could not see others' reactions, so not discouraged from venting painful feelings. Online support can compensate when participants do not feel good about appearance, do not feel well enough to go out. Asynchronous nature had pros and cons (could use any time, might not get response in timely manner). Other advantages: do not have to travel, good for those who are geographically isolated. In CHESS, groups are size-limited, so people can create more intimate ties. Even with size limitations, still get an abundance of messages, membership requires a serious time commitment. Motivations: CHESS groups provide support especially when family members do not understand the stresses of living with breast cancer, may change over time—start out needing support/information then become a provider of support/information. Benefits: realizing that others have similar problems—helps to feel less isolated; reducing uncertainty; knowing what to expect from noxious treatments, altruism, and showing caring to others in group help take focus from preoccupation with self to others; social comparison ("maybe what you have isn't so bad compared to someone else"). |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 75. Shaw LH, Gant LM. In defense of the Internet: the relationship between Internet communication and depression, loneliness, self-esteem, and perceived social support. *Cyberpsychology and Behavior* 2002;5:157-71. [Acceptability] | 40 undergraduate students | Social support: home computer with Internet | Web site with chat rooms, requiring login name and password to enter | Participants engaged in five structured chats with an anonymous partner from the study. | Depression, loneliness, social support, self-esteem | Scores on depression and loneliness scales decreased, and scores on social support and self-esteem scales increased, indicating positive effects over time. |
| 76. Tang PC, Black W, Buchanan J, Young CY, Hooper D, Lane SR. PAMFOnline: integrating ehealth with an electronic medical record system. *Proceedings of the American Medical Informatics Association Symposium* 2003:649-53. [Acceptability, Applicability] | 914 adults recruited from the Palo Alto Medical Foundation; gender equally split, mean age 52 | Patient-provider interaction/ electronic medical record: home computer with Internet | PAMFOnline provides access to summary data from medical records: users can view test results, make appointments, refill prescriptions, update demographics, view doctor-approved health information, get advice from doctors and nurses. All services were available free, except messaging service, which required a nominal subscription fee. | Surveyed users of PAMFOnline, conducted focus groups to determine who would be the most likely users. | Satisfaction | Survey findings: 73% satisfied with existing functionality. Majority of users ranked viewing lab test results as most important benefit. Online messaging with clinicians also rated highly, even though this was available only with an extra charge. Patients wanted more of the medical record available to them, especially old lab results. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 77. Weis R, Stamm K, Smith C, Nilan M, Clark F, Weis J, et al. Communities of care and caring: the case of MSWatch.com. *Journal of Health Psychology* 2003;8:135-48. [Acceptability] | 943 adults; 76% female, mean age 43.7 | Multiple sclerosis (MS): home computer with Internet | MSWatch.com: a Web site designed for patients with MS. Site provides information (community news, humor, ask-an-expert, personal stories, tips, library, newsletter, diary, and MS news) and support (chat rooms, discussion groups, instant messaging, e-mail, and postcards). | Users of MSWatch were surveyed. | Perceived usefulness of information and support functions | Information functions showed greater perceived usefulness than support features. Only between 10% and 30% of users found the support features useful. Usefulness of the Web site was greater for those in the early stages of the disease and then again in the third year of the disease. Use of support features did not relate to disease progression. Those using the Web site to answer general questions rated the information as useful, while those who were referred to the site by other MS patients found the support features useful. Women rated the information function of greater importance than males. Adults with children rated both support and information functions higher than those without children. Younger people rated the support functions more highly than older people did. The highest rating of the site overall came from those who found it useful for information and support. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 78. Wilkie D, Huang H, Berry D, Schwartz A, Lin Y, Ko N, et al. Cancer symptom control: feasibility of a tailored, interactive computerized program for patients. *Family and Community Health* 2001;24:48-62. [Acceptability] | 41 outpatients with cancer; age 18 or older; all participants were white except for one Asian; 26% had never used computer | Pain management: clinic-based computer program with touch screen | SymptomReport is a software program that asks questions about pain and fatigue. SymptomConsult provides tailored management strategies. | Two groups of patients: all used SymptomReport, saw doctor, then randomly interacted with SymptomConsult or computer games; 4 weeks later completed SymptomReport again. | Completion time, acceptability | Mean completion time for SymptomReport was less than 40 minutes, for SymptomConsult 20 minutes. High acceptability scores for SymptomReport; some felt SymptomConsult was not targeted to their needs or provided no new information. Some reported they had increased understanding, awareness, and medical compliance. |
| 79. Wilkie D, Judge M, Berry D, Dell J, Zong S, Gilespie R. Usability of a computerized PAINReportIt in the general public with pain and people with cancer pain. *Journal of Pain and Symptom Management* 2003;25:213-24. [Acceptability] | 213 patients with pain. Outpatients: N=10, all white, 40% male and 60% female; Inpatients N=106, 46% male and 64% female, 86% white and 14% people of color; general public N=97, 58% male and 42% female, 73% white and 27% people of color | Pain management: clinic-based computer program with touch screen | PAINReportIt is a computerized version of the McGill Pain Questionnaire. | Three different groups of participants interacted with PAINReportIt. | Completion time, completeness of pain data, acceptability | Mean completion time 15.8 minutes. All gave responses to at least 3/4 domains (location, intensity, quality, pattern). High acceptability overall, with highest acceptability among participants of color. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 80. Woodruff SI, Edward CC, Conway TL, Elliott SP. Pilot test of an Internet virtual world chat room for rural teen smokers. *Journal of Adolescent Health* 2001;29:239-43. [Acceptability] | 18 high-risk youth recruited from 6 small alternative schools; mean age 15, 66% male; 55% Caucasian, 28% Hispanic, 17% other | Smoking cessation: school computer with Internet | Breathing Room: Internet-based virtual "world" in which young smokers interact with a trained cessation facilitator and with each other; primarily offered chat, also created billboards to address teens' reasons to quit smoking and coping strategies. Also had access to links, shopping, and other features. | Participants interacted with facilitator and other teens in chat room for seven 1-hour sessions. | Acceptability, attitudes about quitting, quitting, intentions | Participated in an average of 5.3 out of 7 sessions, 95% would recommend this to another teen smoker. Positive but not significant changes in "abstinence in the past week" from pretest to posttest. 39% called themselves former smokers at posttest, maintained at 1-month followup. Reduction in number of cigarettes smoked, intention to quit greater, attitudes toward quitting more positive. |
| 81. Zarcadoolas C, Blanco M, Boyer JF. Unweaving the Web: an exploratory study of low-literate adults' navigation skills on the World Wide Web. *Journal of Health Communication* 2002;7:309-24. [Availability] | 24 adults with low-literacy, low incomes; 17 Hispanic, 3 African American, 2 Asian, 2 white; recruited from literacy or computer classes at community-based organizations; 10 reported owning computers, 15 had used the Internet before. | Health information: lab computer with Internet | Specific Web sites on the World Wide Web | Participants were asked to assess the content and information available on specific Web sites as well as perform specific tasks. Methods used included observation, contextual inquiry, and a think-aloud protocol. | Satisfaction, navigation | 23/24 excited to use Internet. 23/24 thought they would use Internet more in next few years. Navigation difficulties: scrolling, using back arrow, typing/spelling to enter Web address, using graphic links. 11/24 thought people should not trust everything on Web, 9/24 thought they should trust everything, 4/24 not sure. None could identify how to determine what to trust. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 82. Zimmerman DE, Akerelrea CA, Buller DB, Hau B, Leblanc M. Integrating usability testing into the development of a 5 a day nutrition Website for at-risk populations in the American Southwest. *Journal of Health Psychology* 2003;8:119-34. [Appropriateness] | Study 1: 43 adults; mean age 42.8, 32% income <$15,000, 61% Hispanic/Latino, 15% Native American, 24% Caucasian; 91% had computer experience.<br>Study 2: 35 participants; mean age 43.7, 74% women, 25% income <$15,000, 47% Hispanic/Latino, 26% Native American, 27% other (8 white, 1 Asian); 66% with more than 1 year computer experience, 34% with less than 1 year experience.<br>Study 3: 31 adults; mean age 43, 60% female; 35% income <$15,000, 42% Hispanic/Latino, 35% Native Americans, 23% Caucasians | Nutrition: lab computer with Internet | "5 a Day, the Rio Grande Way": a nutrition education Web site for multicultural adults living in southern Colorado and northern New Mexico | Study 1: card-sorting task used to identify how target population categorized nutrition concepts.<br>Study 2: talk aloud protocol and observation as users interacted with a prototype Web site.<br>Study 3: same protocol as study 2, but with a larger and near-final version of the Web site | Categorization of nutritional concepts; satisfaction and ease of use | Card-sort task results were used to create the site map for the Web site. Study 2 found that most users (86%) were satisfied with the Web site, 85% found it easy to use. Observation showed some areas of difficulty including: assumption of user content knowledge that was lacking, text type too small, unclear titles, participants reluctant to use page links, some difficulty initially locating information, need for additional visuals.<br>Study 3 found that 83% found site interesting, 74% useful, 55% easy to read. Observation showed problems with navigation and locating information. Of the study participants, about 33% had never used computers, and they had difficulty with the hand-eye coordination required for navigating the site, recognizing navigational aids, and understanding the Web site organization and structure. Mouse skills were difficult for users with physical impairments. Only 23% completed all 12 tasks in the protocol. This version was less well-received than previous prototype. Those with more computer experience reported that the site was easier to use. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| **Content Analyses** | | | | | | |
| 83. Cheh, JA, Ribisl KM, Wildemuth, BM. An assessment of the quality and usability of smoking cessation information on the Internet. *Health Promotion Practice* 2003;4(3):278-87. [Appropriateness] | NA | Smoking cessation: lab computer with Internet | Smoking cessation Web sites | Reviewed 30 Web sites identified from online and print resources | Informational content, accessibility and usability, source credibility, currency of information | Majority of sites contained information content congruent with published smoking cessation guidelines. 93.3% of sites written above a fifth-grade Flesch-Kincaid reading level; 9 sites contained >50 pages of content; 16 had site map or search mechanism; 63.3% were created by organizations with authors having health credentials; 3 sites supported claims with reference to scientific research; 5 sites displayed when their content was last updated. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 84. Evers KE, Prochaska JM, Prochaska JO, Driskell M, Cummin CO, Velicer WF. Strengths and weaknesses of health behavior change programs on the Internet. *Journal of Health Psychology* 2003;8:63-70. [Appropriateness] | NA | Health information: lab computer with Internet | 37 public Web sites on health behavior change for disease prevention and management | 273 Web sites addressing 7 targeted problem areas (tobacco use, physical activity, alcohol, diet, diabetes, depression, and pediatric asthma) were identified and screened according to quality criteria that would determine whether the sites had the minimum criteria for having the potential to change behavior. 15% (42) of the programs met 4 of 5 of the criteria, and these sites underwent a full review. | The five "A's" for effective health behavior change treatment on the Internet (advise, assess, assist, anticipatory guidance, and arrange followup), use of behavior change theory, single vs. multiple behaviors, interactivity, security, privacy and confidentiality, accountability, evaluation | Found that the types of assessments varied across types of programs; 81% of programs gave a rationale for the assessment; 84% of the programs provided feedback that followed appropriately from the assessment, although only five used individualized, tailored feedback; 73% offered some form of anticipatory guidance to prevent relapse; 11% specified when a user should come back, and 22% used e-mail reminders to keep in contact; 29% explicitly stated use of a theoretical model; 78% were part of a site addressing multiple risk behaviors. Interactive features included assessments (100%), chat room (49%), bulletin boards or discussion lists (73%), ask-the-expert (49%), behavior tracking tool (49%), e-mail reminders or newsletters (70%). 76% required registration with a password to access all of site. 92% posted a privacy policy statement. 100% had some form of contact, either e-mail or phone. None of the sites included information about evaluation for effectiveness. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 85. Fahey D, Weinberg J. LASIK complications and the Internet: is the public being misled? *Journal of Medical Internet Research* 2003;5:e2. [Appropriateness] | NA | LASIK surgery: lab computer with Internet | Web sites about LASIK surgery | Content analysis of 21 Web sites related to LASIK surgery | Authorship (recognized authority, credentials, contact information), content (details of complications, easy to understand, ease of locating complications, accuracy of references, currency, balanced information), and technical quality (quality of page layout, ease of identifying site's header and footer). | 17/21 sites were commercial; 5/21 (24%) had no information on complications. Of the 16 sites that had information on complications: the author of the information was clearly identified in 5 (31%), the content was referenced in 2 (12.5%), and evidence of the information having been updated was seen in 2 (12.5%). |
| 86. Finn J. An exploration of helping processes in an online self-help group focusing on issues of disability. *Health and Social Work* 1999;24:220-31. [Acceptability] | NA | Social support: lab computer with Internet | An online group whose purpose was to allow discussion and support between individuals coping with physical or mental limitations | Analyzed 3 months of messages from an online support group | Types of posts | Messages focused on health and disability-related information (38.2% of posts), emotional and interpersonal issues related to disability (28.4%), empowerment of members through legal and political means (11.2%), plus more than 1/10 messages devoted to social interchange unrelated to issues of health or disability. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 87. Madan AK, Frantzides CT, Pesce CE. The quality of information about laparoscopic bariatric surgery on the Internet. *Surgical Endoscopy* 2003;17:685-7. [Appropriateness] | NA | Bariatric surgery: lab computer with Internet | Web sites about laparoscopic bariatric surgery | Evaluation of 119 Internet sites found via 6 search engines and 2 metasearch engines. The first 20 "hits" for each separate search engine were included in the study. | Educational information on laparoscopic obesity surgery, discussion of at least one procedure related to the surgery, procedure details, discussion of other procedures, discussion of risks, including death, and discussion of this surgery as an option for obesity surgery. Sites were also evaluated for inclusion of misleading or biased information. | A total of 602 hits found with search engines. Of these, only 119 unique sites. Of these, 63/119 had educational information about bariatric surgery, 56 discussed laparoscopic surgery as an option, 33 gave details of the procedure, 30 discussed accurate weight loss results, 26 discussed death as a complication, 18 contained biased or misleading information. Only 89 of the original 602 hits led to sites that discussed this type of surgery, procedure details, and complications in an unbiased manner. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 88. McTavish FM, Pingree S, Hawkins R, Gustafson D. Cultural differences in use of an electronic discussion group. *Journal of Health Psychology* 2003;8:105-17. [Overview, Applicability] | 113 women who received the Comprehensive Health Enhancement Support System (CHESS) and who had participated in the discussion group; 86 white, 23 African American, 2 Native American, 2 Asian | Cancer: lab computer with Internet | CHESS breast cancer module: study focused on use of the Women's Only Discussion Group, which only allowed access to women with breast cancer. | Messages from the discussion group were randomly selected for analysis. | Use of discussion group, message content | Women of color used the discussion group significantly less than Caucasian women. Most of their use was in the first 3 months, while the Caucasian women's use of the discussion group declined much more gradually. Women of color wrote a greater proportion of messages specific to breast cancer and its treatment, and fewer dealing with daily life than Caucasian women. The groups did not differ in self-disclosure, but Caucasian women were more likely to offer support to other women. Message focus changed over time. Caucasian women wrote more about daily life than breast cancer as time went on. Women of color initially wrote more about breast cancer, and then overall usage dropped off significantly. |
| 89. Mendelson C. Gentle hugs: Internet listservs as sources of support for women with lupus. *Advances in Nursing Science* 2003;26:299-306. [Acceptability] | NA | Lupus: lab computer with Internet | Three online listservs for women with lupus | Three online listservs for women with lupus were identified. Content analysis of posting was completed. | Types of posts | Themes emerged: exchanging information and advice, living with illness, life goes on/friendly banter; life in cyberspace (introduction of self to list/welcome from member), support. |

| Table Reference Number/Authors/ Text Section | Sample | Health Topic Area/Locus of Use/ Technology | Description of the Tool | Overview | Measures | Outcomes |
|---|---|---|---|---|---|---|
| 90. Oermann M, Lowery N, Thornley J. Evaluation of Web sites on management of pain in children. *Pain Management Nursing* 2003;4:99-105. [Appropriateness] | NA | Pain management: lab computer with Internet | Web sites about pain management | 40 Web sites identified from Google and MSN were rated for quality using the Health Information Technology Institute (HITI) criteria (credibility, content, disclosure, links, design, interactivity, and caveats). | Quality, readability | 9/40 sites met all of the HITI criteria and were at an appropriate reading level for most users. The mean reading grade level of all sites was 10.8—too high for many consumers. |
| 91. Seidman J, Steinwachs D, Rubin H. Design and testing of a tool for evaluating the quality of diabetes consumer-information Web sites. *Journal of Medical Internet Research* 2003;5:e30. [Appropriateness] | NA | Diabetes: lab computer with Internet | Web sites about diabetes | Researchers developed a tool, based on the American Diabetes Association's Clinical Practice Recommendations, that would allow evaluation of the quality of diabetes-related Web sites. Then they assessed 90 diabetes-related Web sites using the tool. | Quality | Found wide variation in the quality of consumer diabetes information on the Internet. Average score of 50% suggests substantial level of inaccurate and missing information. |

# APPENDIX 4. A COMPARISON OF INTERNET USE AND HEALTH STATUS OF POPULATIONS THAT EXPERIENCE HEALTH DISPARITIES

This appendix provides side-by-side comparisons of Internet use and health status measures according to the *Healthy People 2010* population categories for which data were available at the time of analysis. Not all health topics have measures for each variable. For example, diabetes has measures for race and ethnicity, gender, education level, geographic location, and age, whereas obesity has measures for race and ethnicity and gender only. These categories are those variables associated with health disparities. The data presented in this section highlight health status measures for diabetes, obesity, asthma, heart disease and stroke, cancer, physical activity, and tobacco use for select populations as well as the related Internet use profiles.

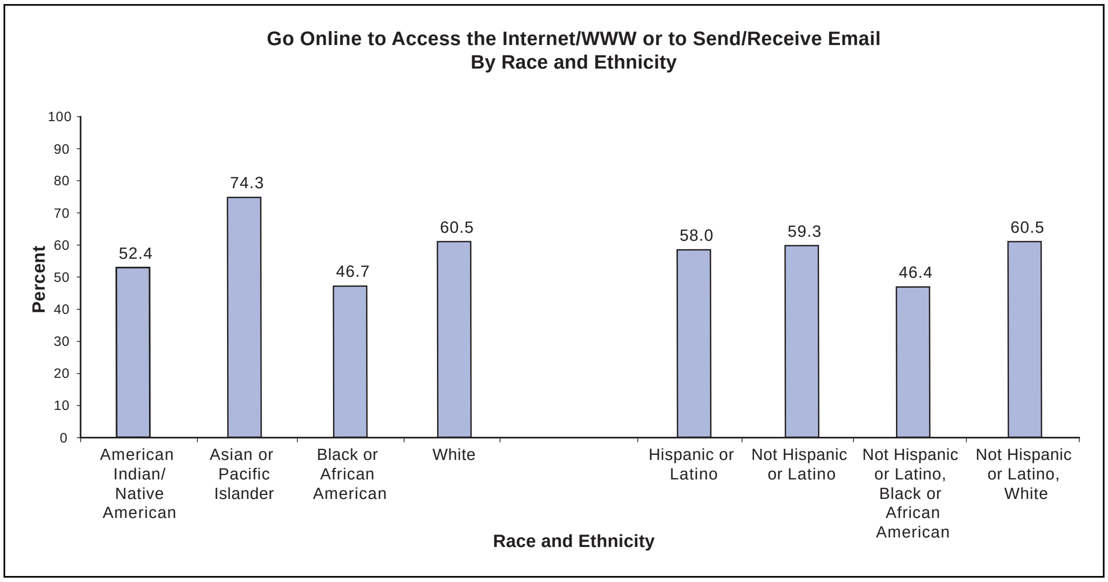
Data from the 2002–2003 Pew Internet & American Life Project's Daily Internet Tracking Survey were the primary source of data for the technology profiles on Internet use. In addition, data from *DATA2010*, the Centers for Disease Control and Prevention's interactive database system for tracking *Healthy People 2010*, were used to present health status data as of January 2004. Although the absolute numbers of persons accessing the Internet were lower in 2002–2003 than in the most current Pew surveys (September 2005), the proportions hold true (S. Fox, personal communication, December 2005. See also *www.pewinternet.org/trends/user_demo_12.05.05.htm*).

# 1. DIABETES

## 1.1 Race and Ethnicity

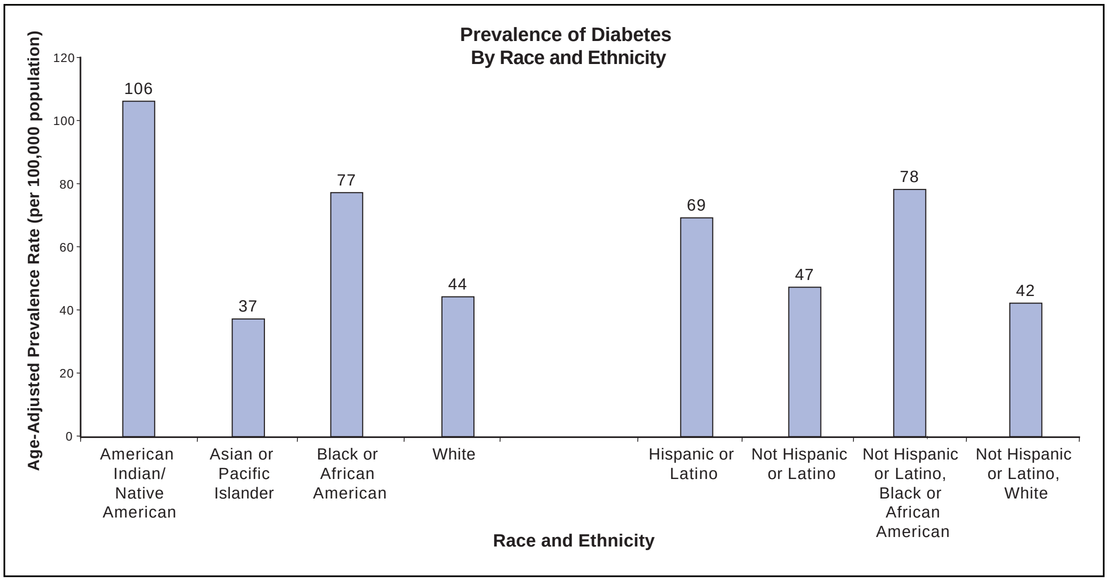
American Indians/Alaska Natives, Hispanics/Latinos, and Blacks/African Americans have higher rates of diabetes compared to other racial and ethnic groups and also have the lowest rates of Internet use (Figures 1 and 2).

*Figure 1*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 2*

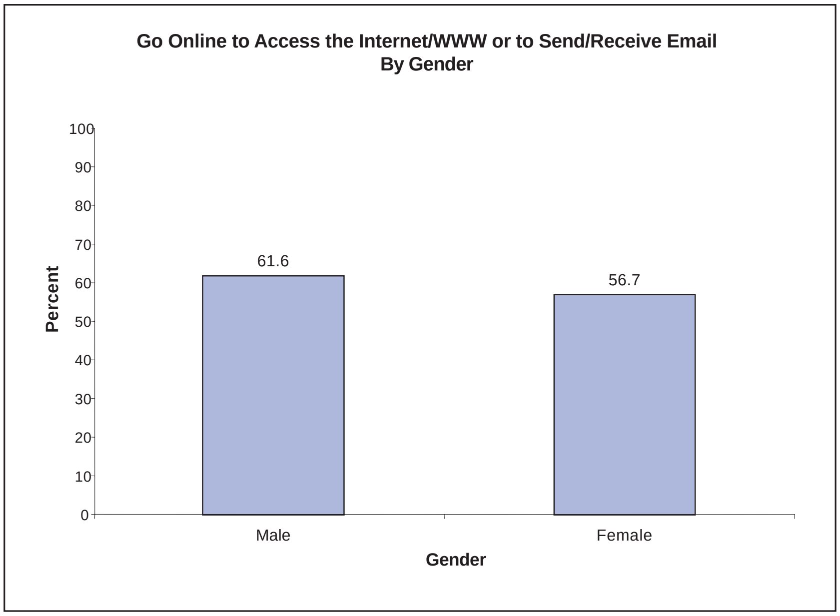


Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database.* Centers for Disease Control and Prevention, January 2004

## 1.2 Gender

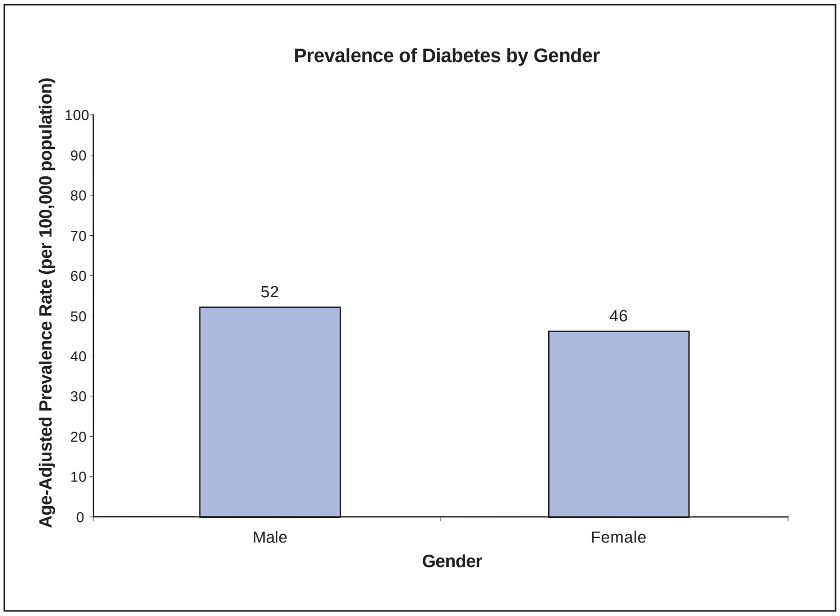
Disparities in diabetes prevalence do not appear to exist between males and females, which is also the pattern with Internet use (Figures 3 and 4).

*Figure 3*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 4*

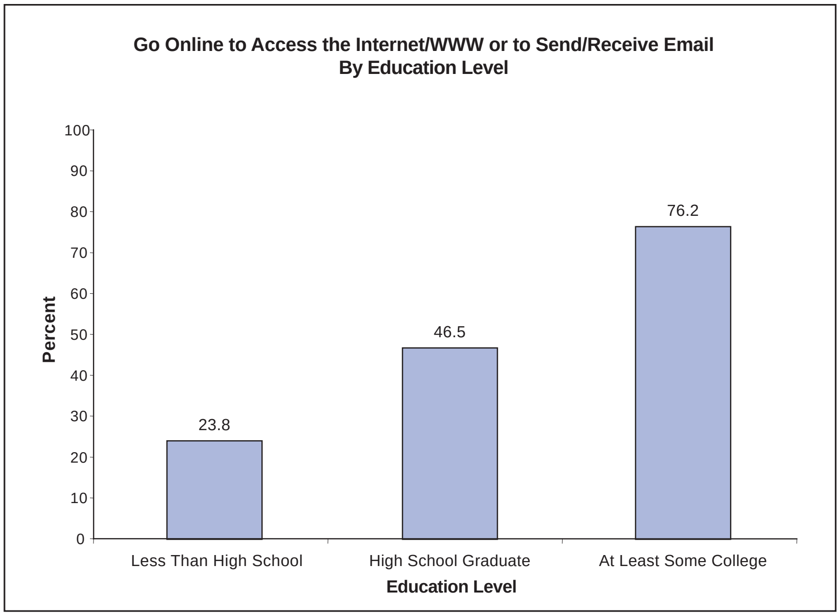


Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database.* Centers for Disease Control and Prevention, January 2004

## 1.3 Education Level

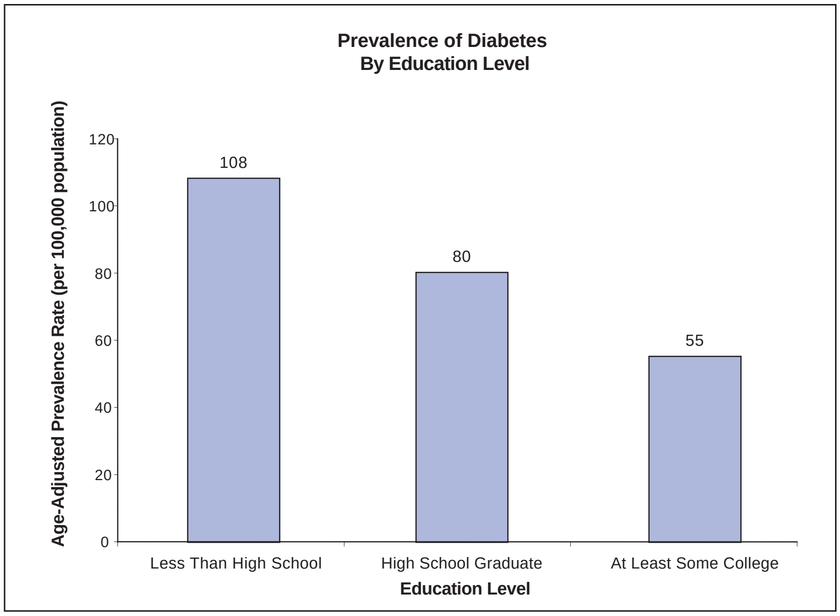
Individuals with lower levels of education have higher rates of diabetes, but they have lower rates of Internet use compared to those with higher levels of education (Figures 5 and 6).

*Figure 5*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 6*

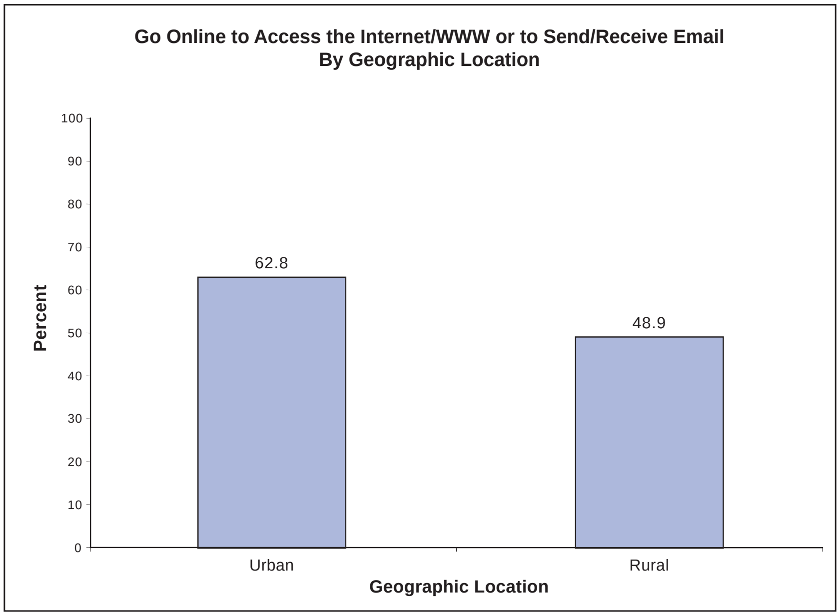


Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database.* Centers for Disease Control and Prevention, January 2004

## 1.4 Geographic Location

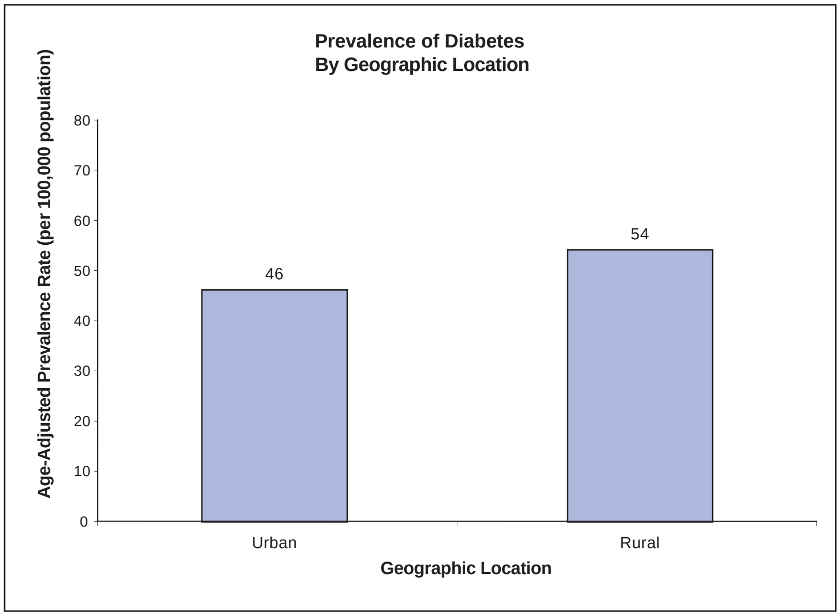
Those living in rural areas experience slightly higher rates of diabetes and also have lower rates of Internet use compared to those living in urban areas (Figures 7 and 8).

*Figure 7*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 8*

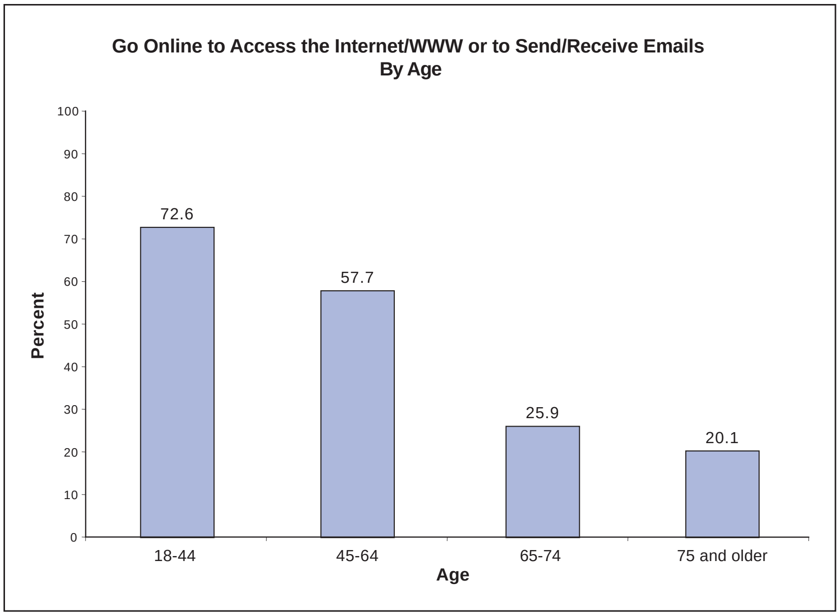


Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database.* Centers for Disease Control and Prevention, January 2004

## 1.5 Age

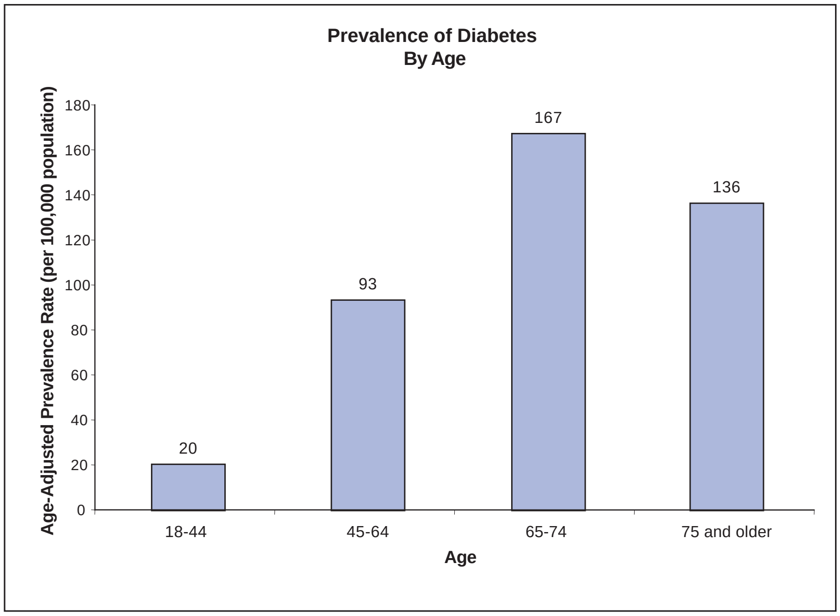
Elderly populations (made up of individuals age 65 and older) have higher rates of diabetes compared to younger populations yet have the lowest rates of Internet use of all age groups (Figures 9 and 10).

*Figure 9*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 10*



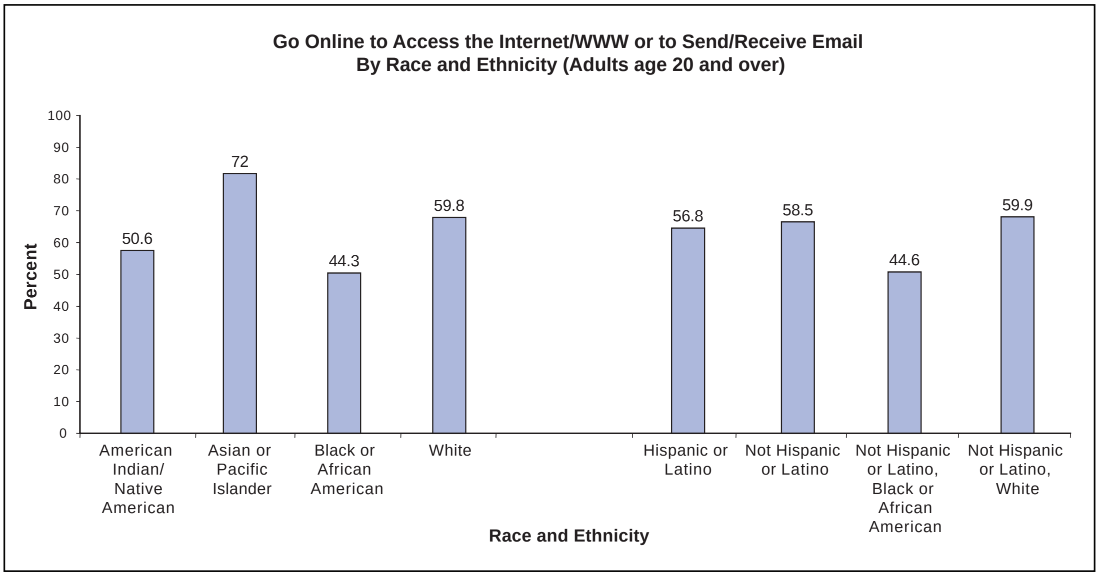
Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database.* Centers for Disease Control and Prevention, January 2004

# 2. OBESITY

## 2.1 Race and Ethnicity

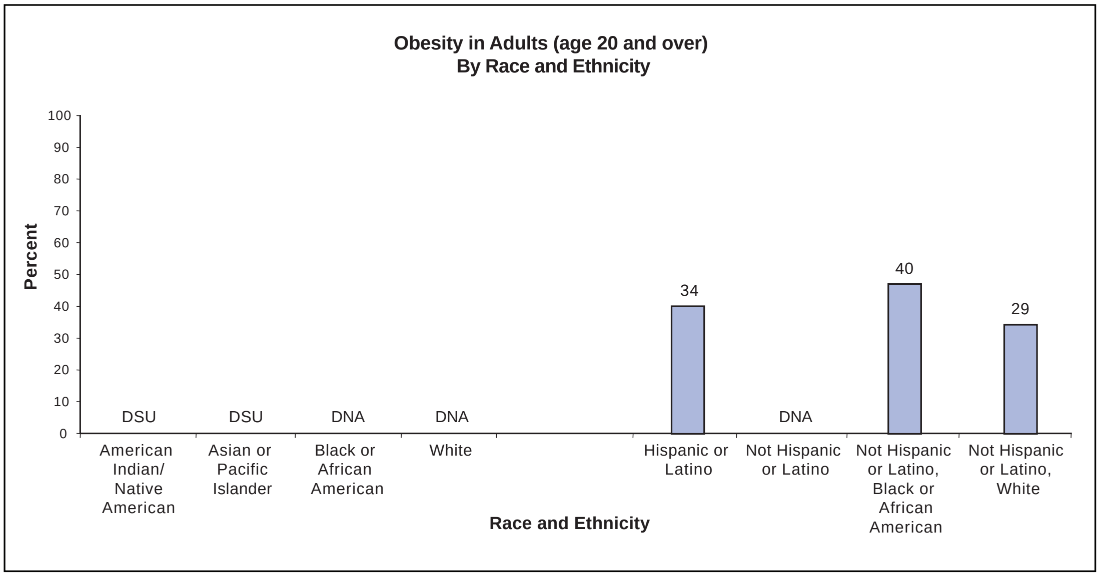
The rate of obesity is slightly higher for Hispanics/Latinos and non-Hispanic Blacks/African Americans compared to non-Hispanic Whites (Figure 12). On the other hand, rates of Internet use for Hispanics/Latinos and Blacks/African Americans are lower than for non-Hispanic Whites (Figure 11).

*Figure 11*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 12*



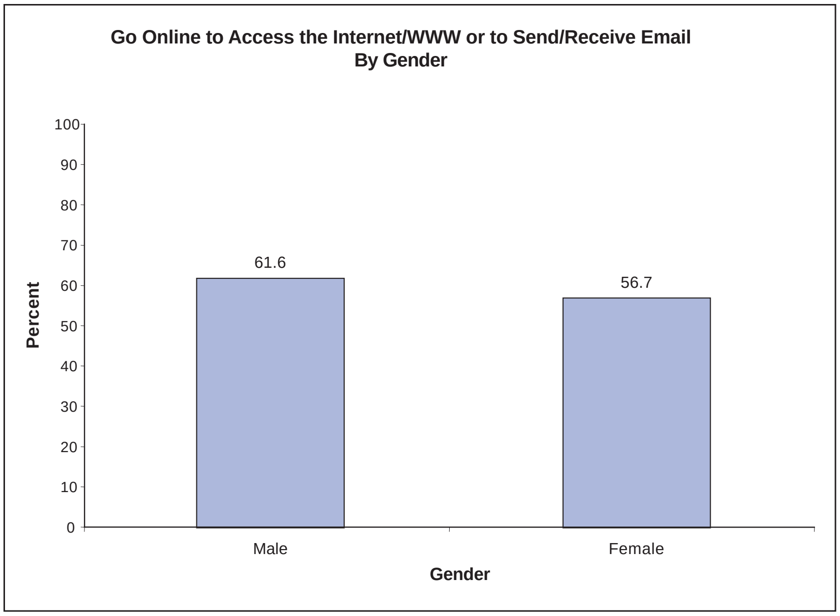
Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database.* Centers for Disease Control and Prevention, January 2004

DSU = Data do not meet the criteria for statistical reliability, data quality, or confidentiality.
DNA = Data for specific population are not collected.

## 2.2 Gender

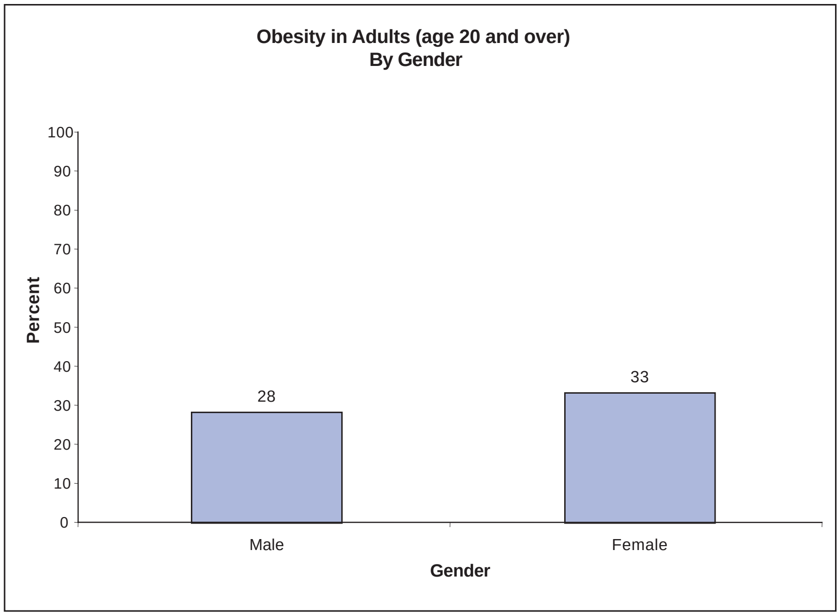
Gender differences in obesity do not appear to be large; similarly, Internet use does not appear to differ largely between males and females (Figures 13 and 14).

*Figure 13*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 14*



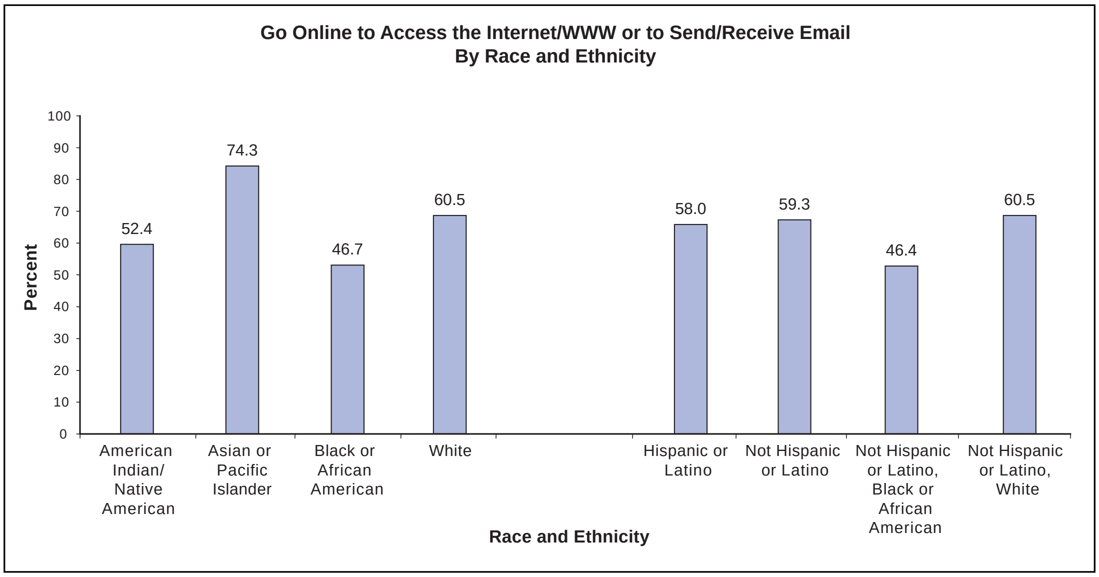
Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database.* Centers for Disease Control and Prevention, January 2004

# 3. ASTHMA

## 3.1 *Race and Ethnicity*

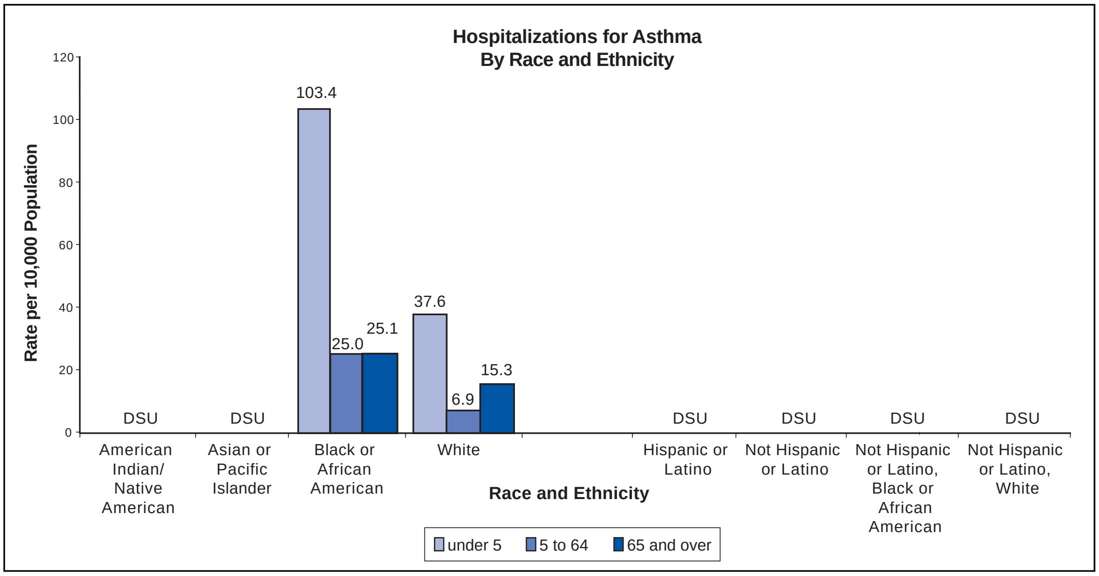
Blacks/African Americans have higher rates of hospitalization for asthma compared to Whites at all ages, but particularly for children under the age of 5 (Figure 16). Yet, Blacks/African Americans have the lowest rate of Internet use among racial and ethnic groups (Figure 15).

*Figure 15*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 16*



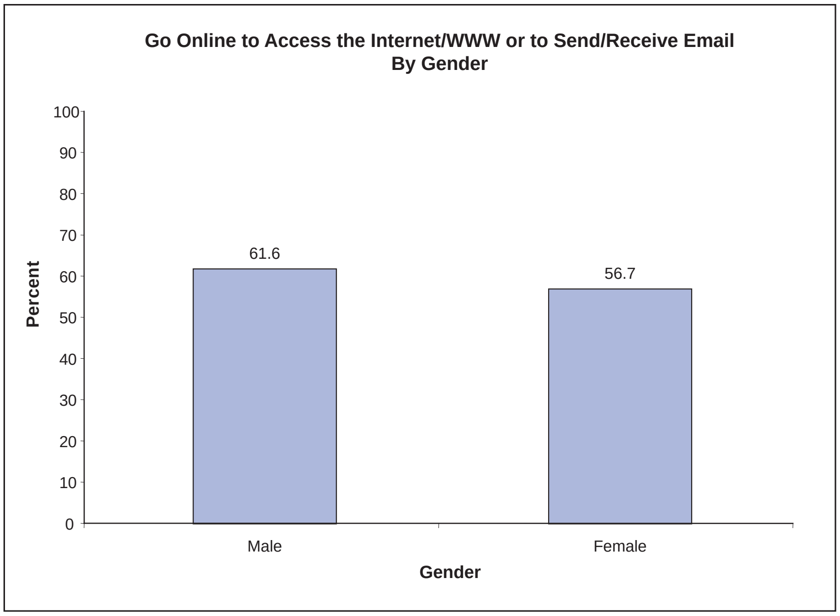
Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database.* Centers for Disease Control and Prevention, January 2004

DSU = Data do not meet the criteria for statistical reliability, data quality, or confidentiality.

## 3.2 Gender

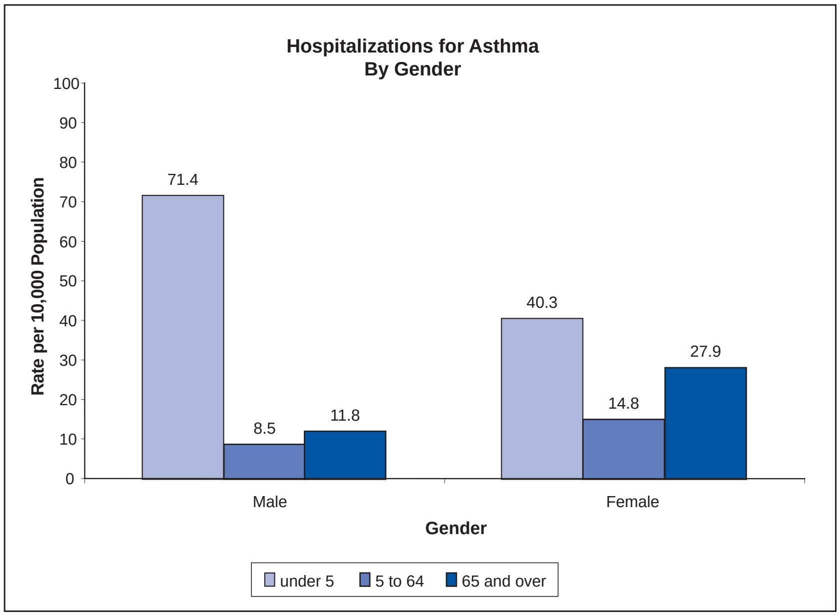
Male children have higher rates of hospitalizations for asthma compared to female children, while older females have higher hospitalization rates compared to older males (Figure 18). Internet use, in general, does not differ largely between males and females (Figure 17).

*Figure 17*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 18*



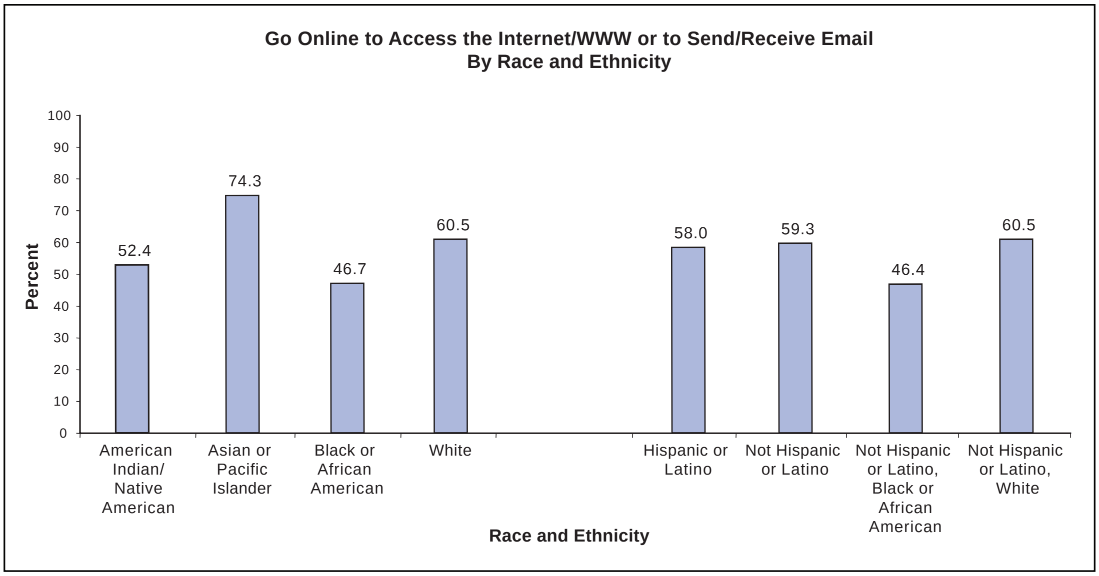
Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database.* Centers for Disease Control and Prevention, January 2004

# 4. CANCER

## 4.1 *Race and Ethnicity*

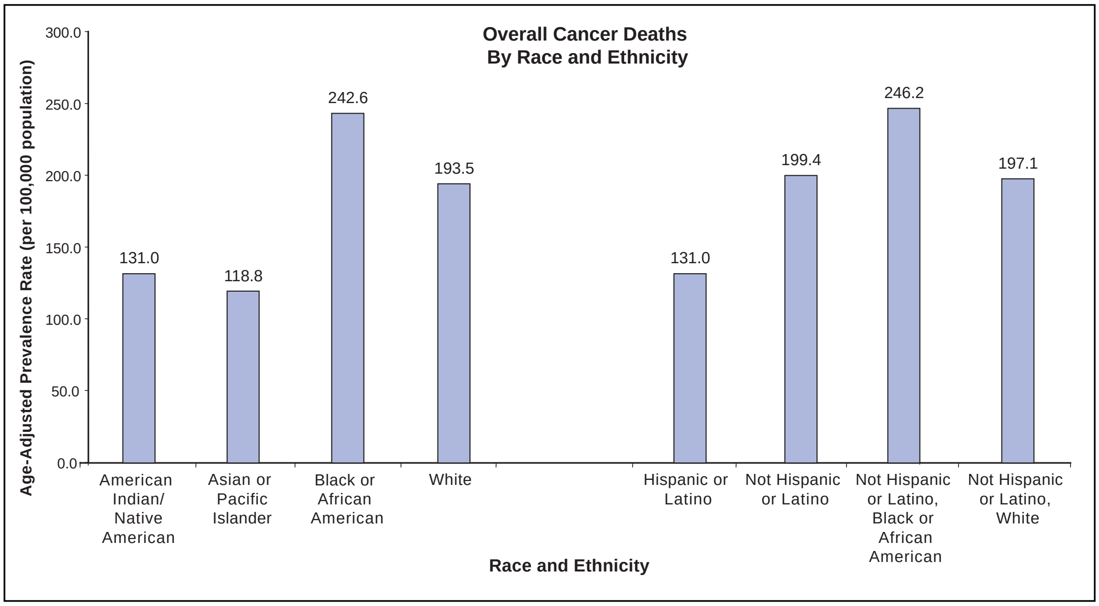
Blacks/African Americans face significant disparities in mortality due to cancer (Figure 20), and as illustrated in Figure 19, they have the lowest rates of Internet use.

*Figure 19*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 20*

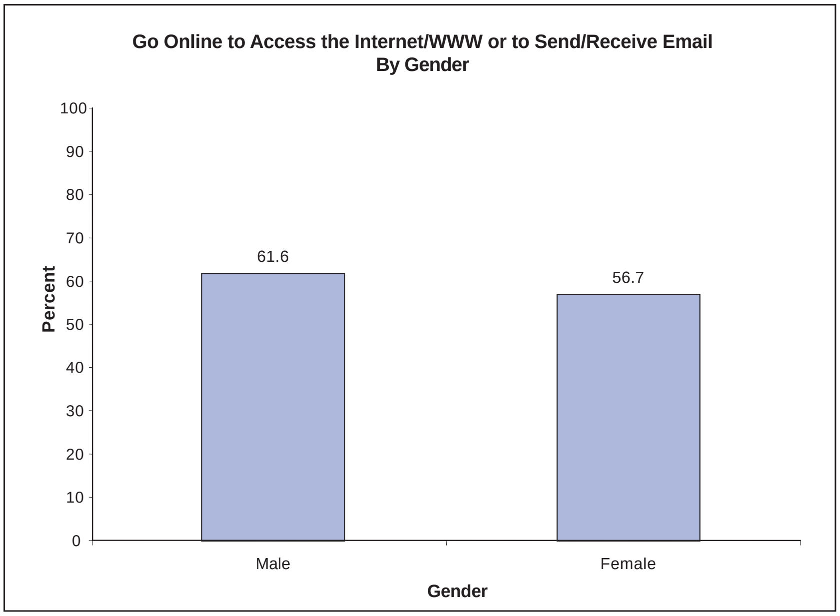


Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database.* Centers for Disease Control and Prevention, January 2004

## 4.2 Gender

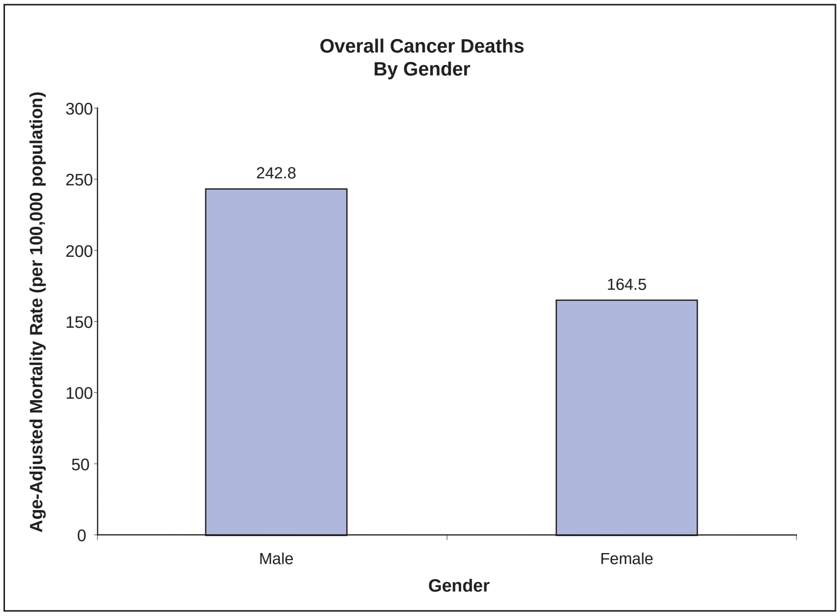
Males have slightly higher rates of overall death due to cancer compared to females (Figure 22). Again, differences in Internet use do not appear to differ largely between males and females (Figure 21).

*Figure 21*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 22*

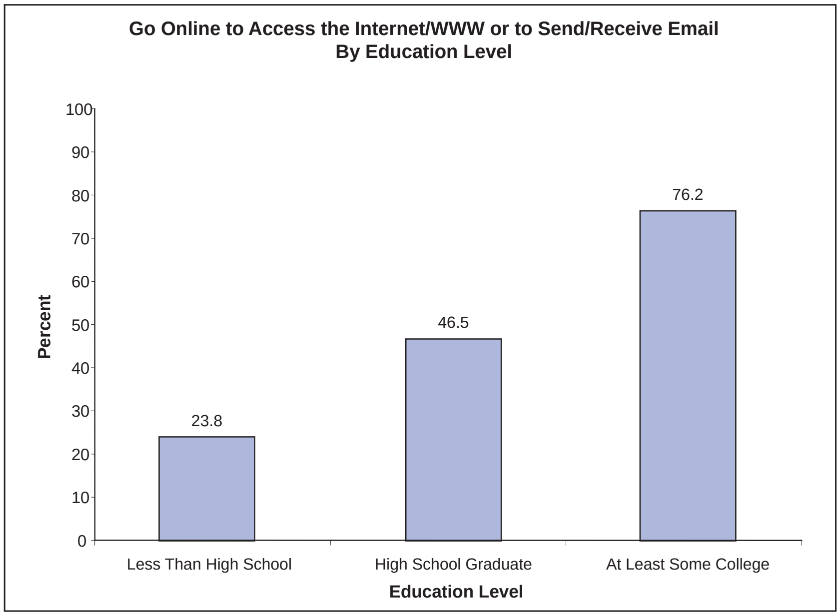


Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database.* Centers for Disease Control and Prevention, January 2004

## 4.3 Education Level

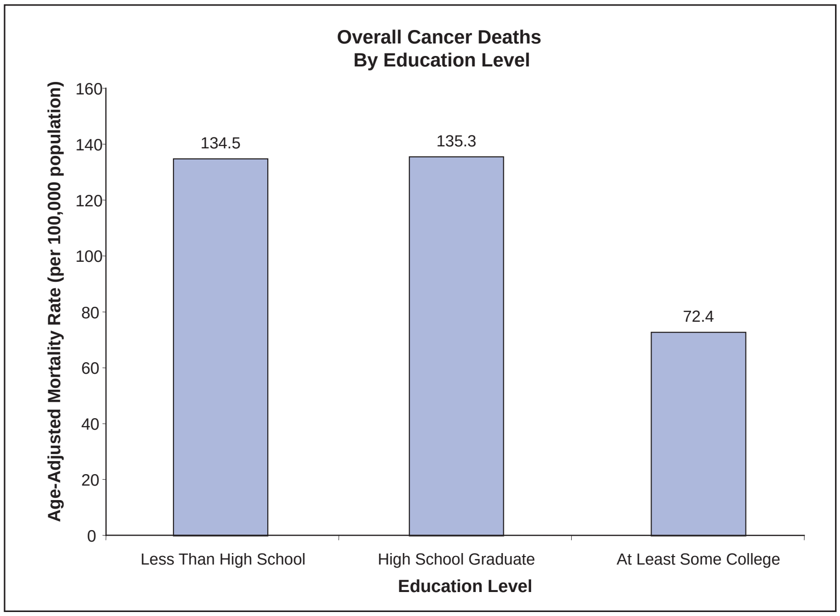
Those with lower levels of education experience much higher rates of death due to cancer but have lower rates of Internet use compared to those with higher levels of education (Figures 23 and 24).

*Figure 23*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 24*



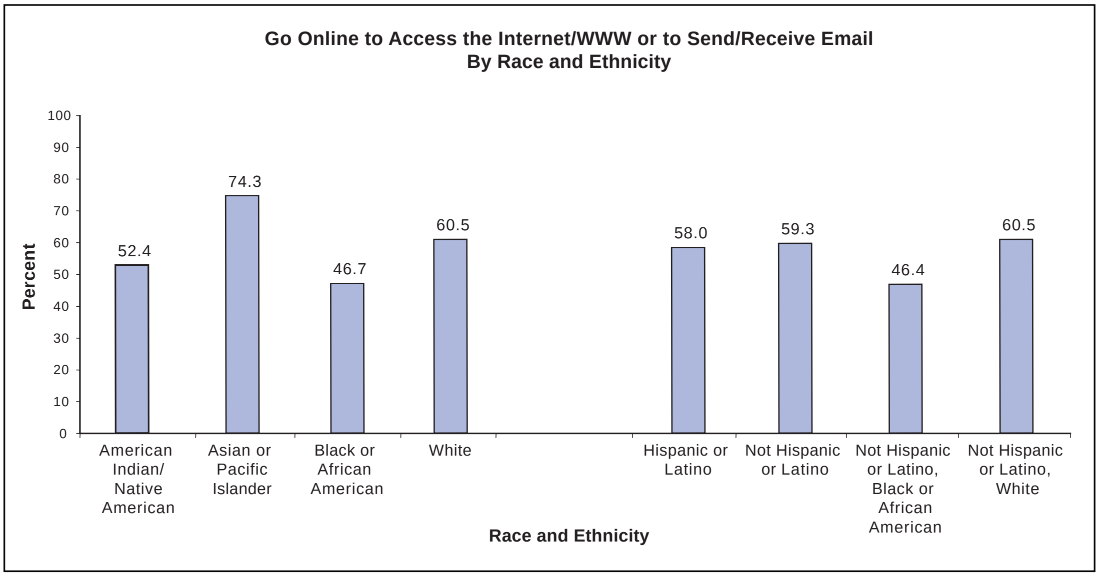
Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database.* Centers for Disease Control and Prevention, January 2004

# 5. HEART DISEASE AND STROKE

## *5.1 Race and Ethnicity*

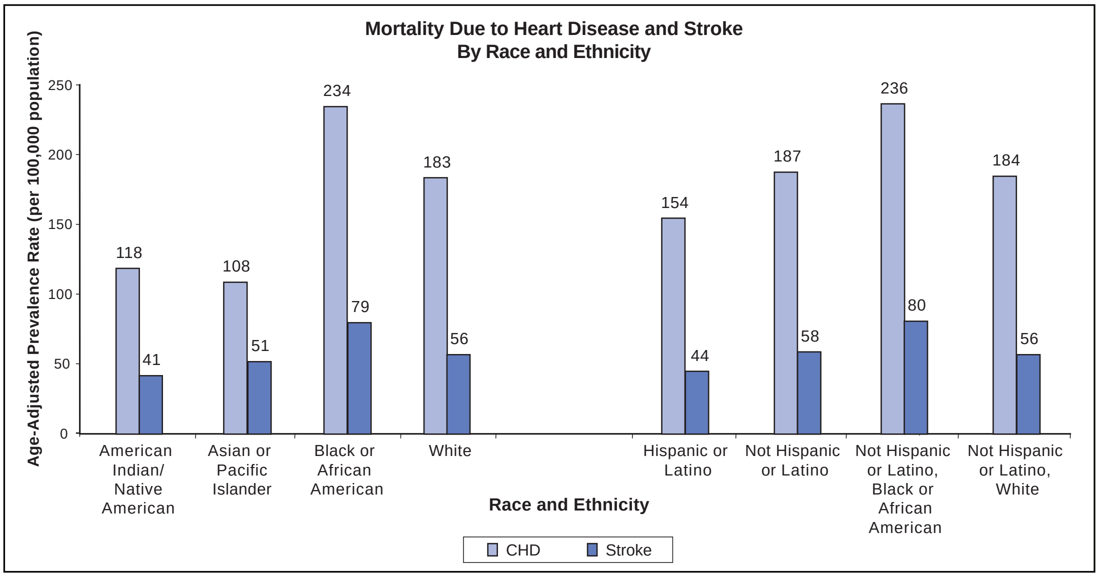
Blacks/African Americans face significant disparities in mortality due to coronary heart disease and stroke compared to members of other racial and ethnic groups (Figure 26). Internet use is also the lowest for this population (Figure 25).

*Figure 25*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 26*

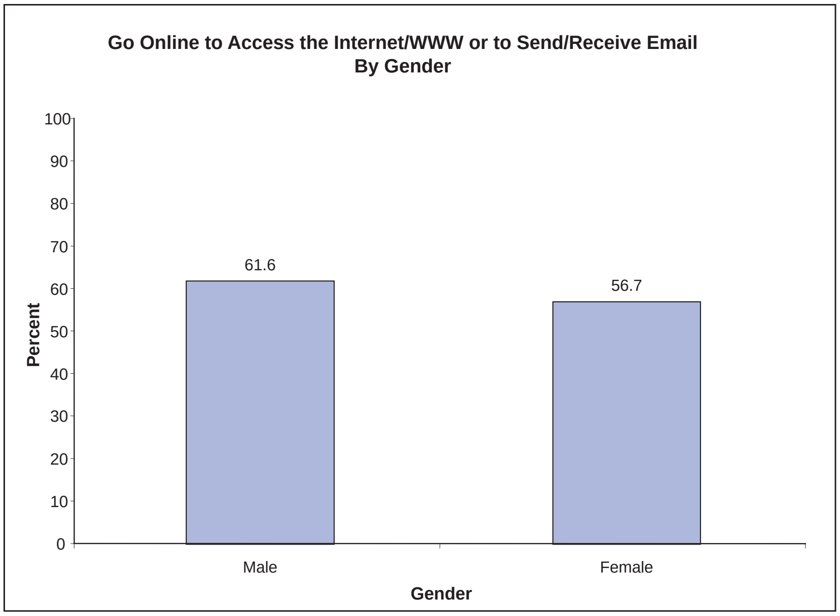


Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database.* Centers for Disease Control and Prevention, January 2004

## 5.2 Gender

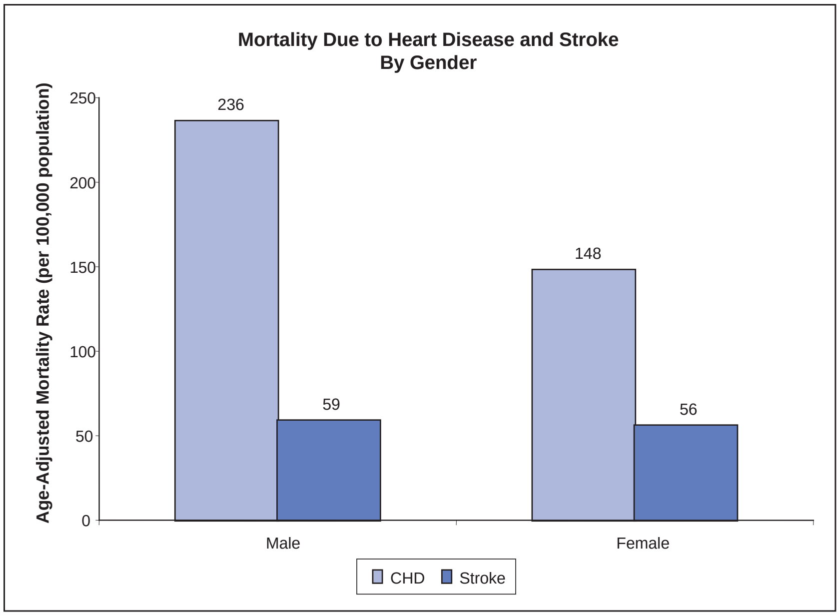
Males have a higher rate of death due to coronary heart disease compared to females (Figure 28). Differences in Internet use do not appear to differ largely between males and females (Figure 27).

*Figure 27*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 28*

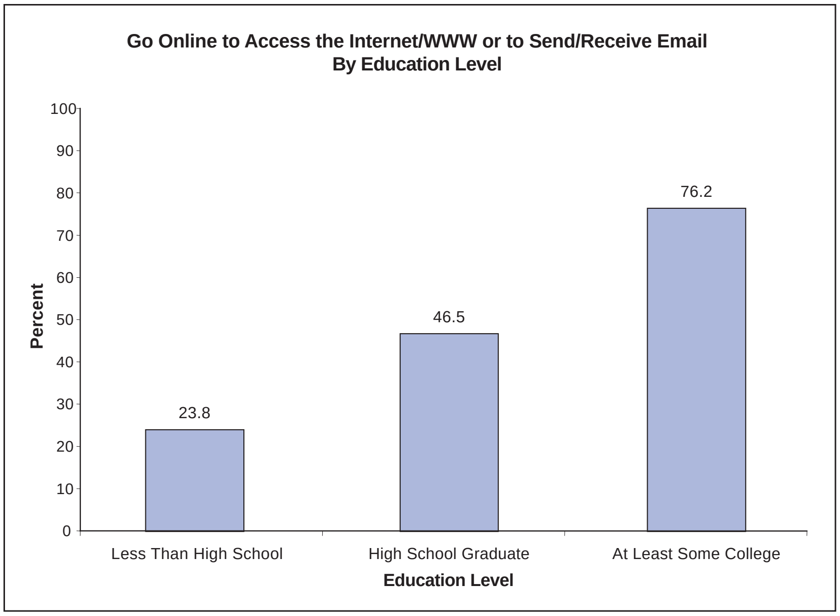


Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database*. Centers for Disease Control and Prevention, January 2004

## 5.3 Education Level

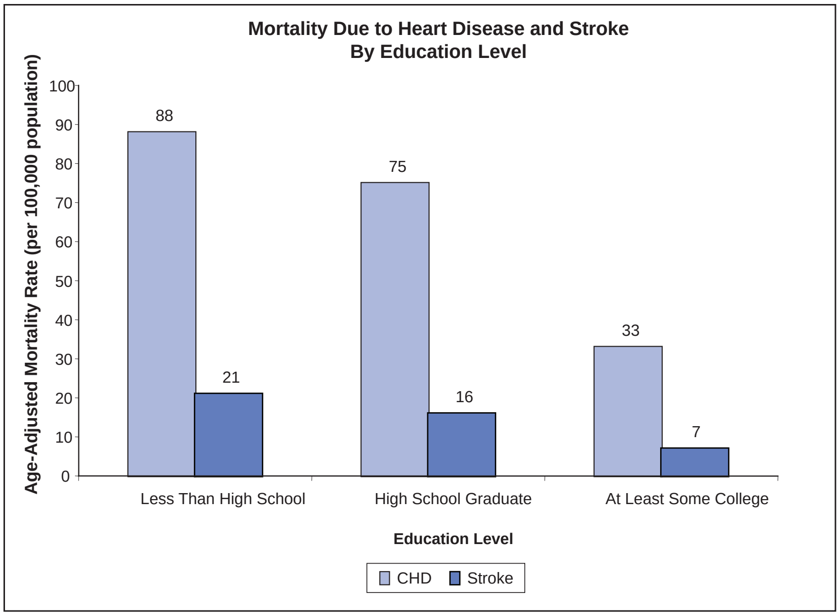
Those with lower levels of education experience much higher rates of death due to heart disease and stroke and also have lower rates of Internet use compared to those with higher levels of education (Figures 29 and 30).

*Figure 29*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 30*



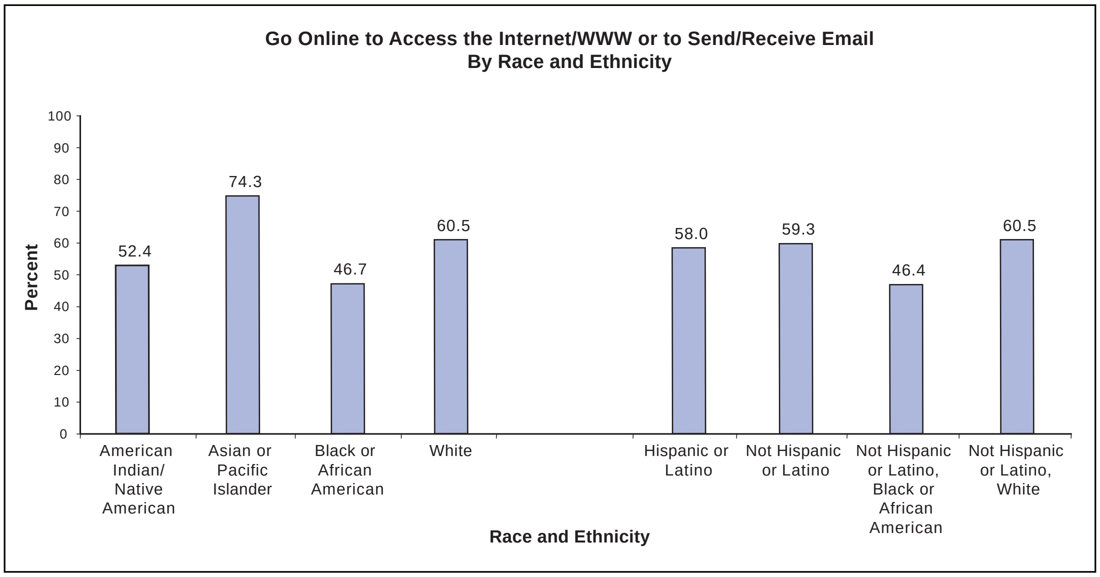
Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database.* Centers for Disease Control and Prevention, January 2004

# 6. MODERATE/VIGOROUS PHYSICAL ACTIVITY

## 6.1 *Race and Ethnicity*

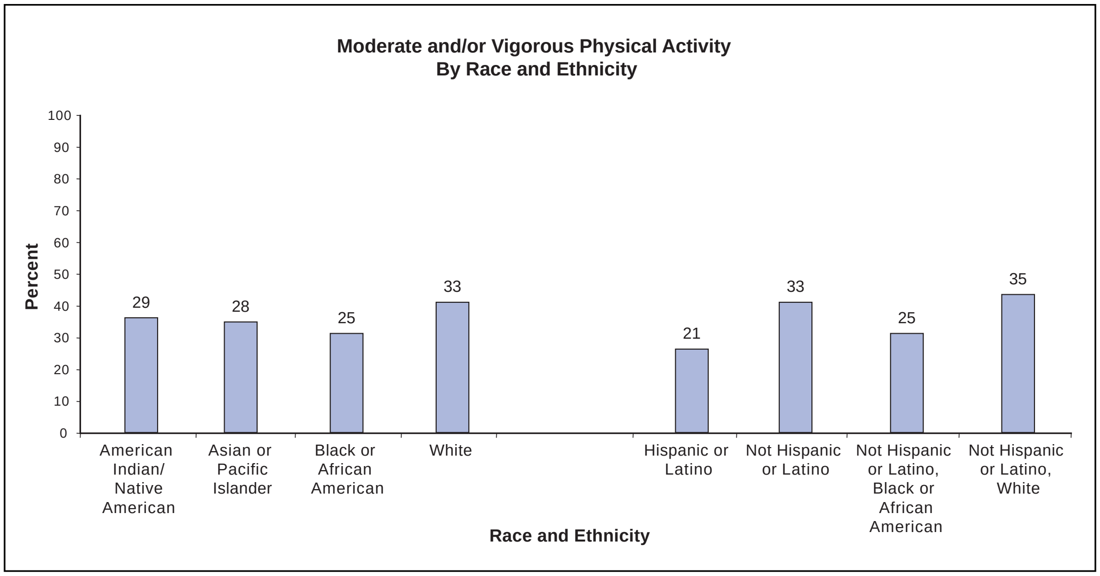
Rates of moderate/vigorous physical activity are slightly lower for racial and ethnic minority populations compared to nonminority populations (Figure 32). Internet use for racial and ethnic minorities, with the exception of Asians or Pacific Islanders, is also lower compared to nonminorities (Figure 31).

*Figure 31*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 32*

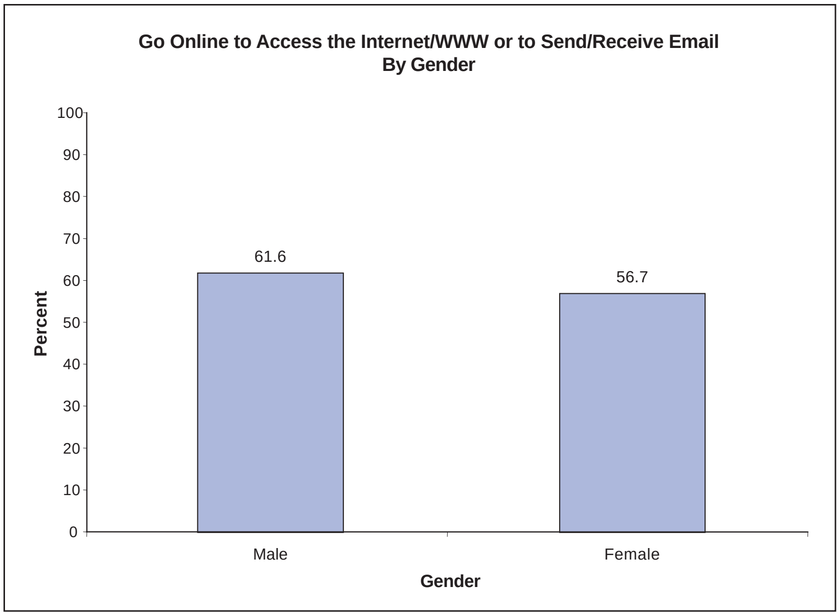


Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database.* Centers for Disease Control and Prevention, January 2004

## 6.2 Gender

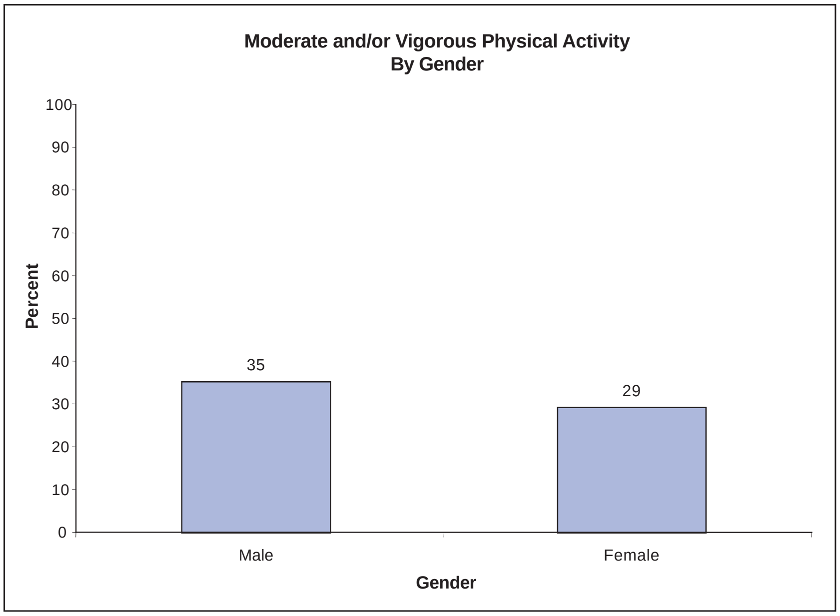
Large differences do not appear to exist between males and females in moderate/physical activity (Figure 34). Differences in Internet use do not appear to differ largely between males and females (Figure 33).

*Figure 33*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 34*

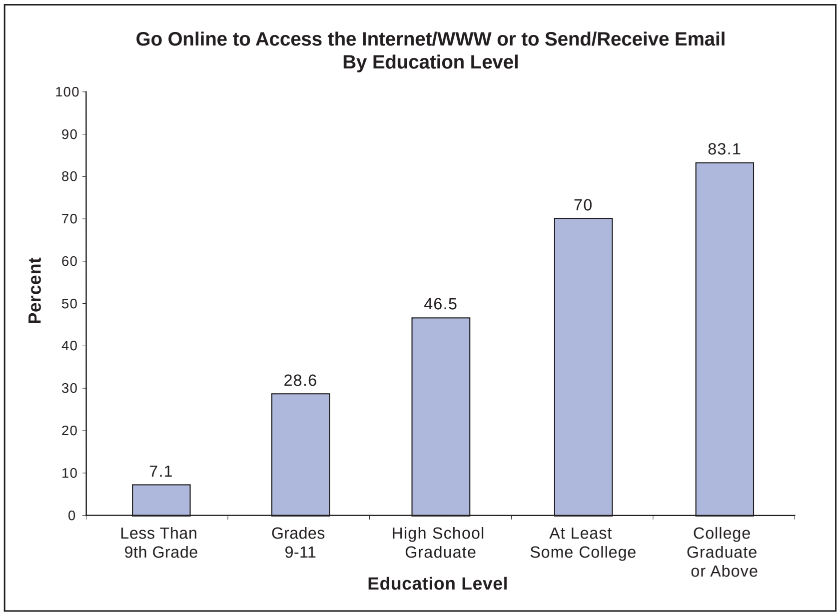


Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database.* Centers for Disease Control and Prevention, January 2004

## 6.3 Education Level

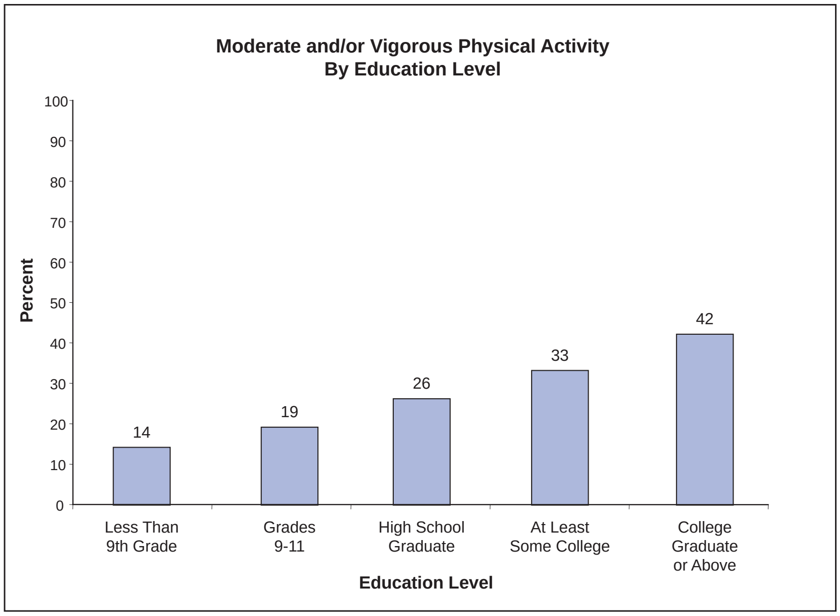
Rates of moderate/vigorous physical activity increase with higher levels of education, as do rates of Internet use (Figures 35 and 36). Less educated persons have lower rates of physical activity and Internet use compared to more educated persons.

*Figure 35*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 36*



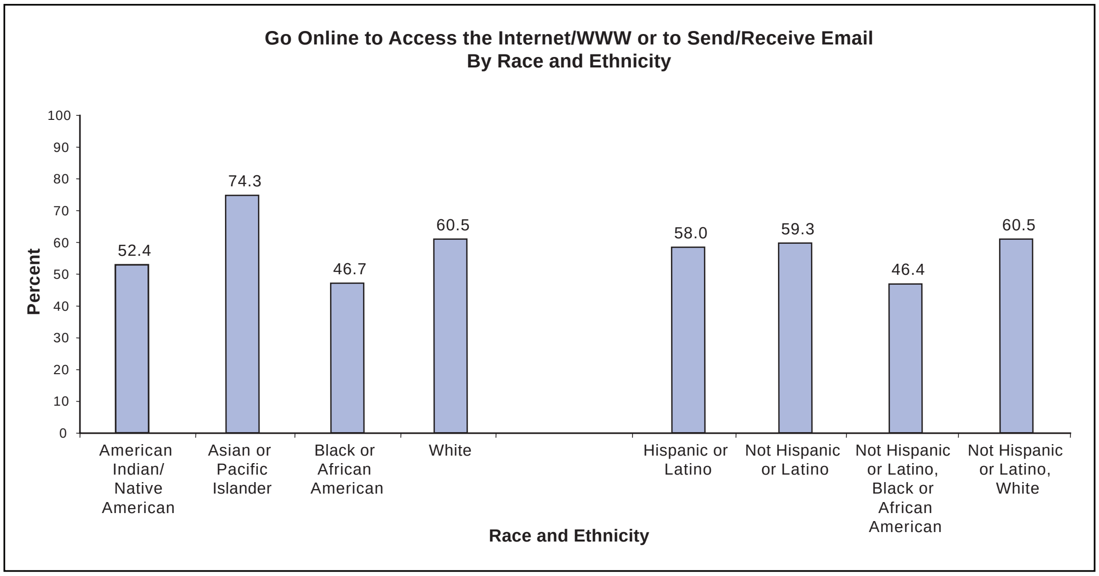
Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database.* Centers for Disease Control and Prevention, January 2004

# 7. TOBACCO USE

## 7.1 Race and Ethnicity

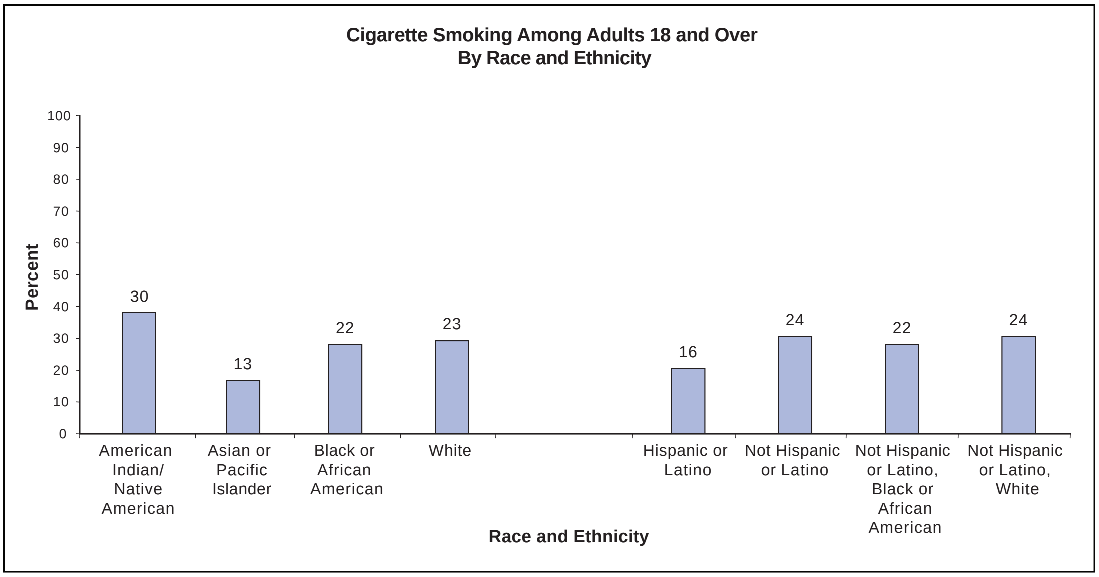
American Indians/Alaska Natives have higher rates of cigarette smoking compared to other racial and ethnic groups (Figure 38) and also have low rates of Internet use, second to Blacks/African Americans (Figure 37).

*Figure 37*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 38*

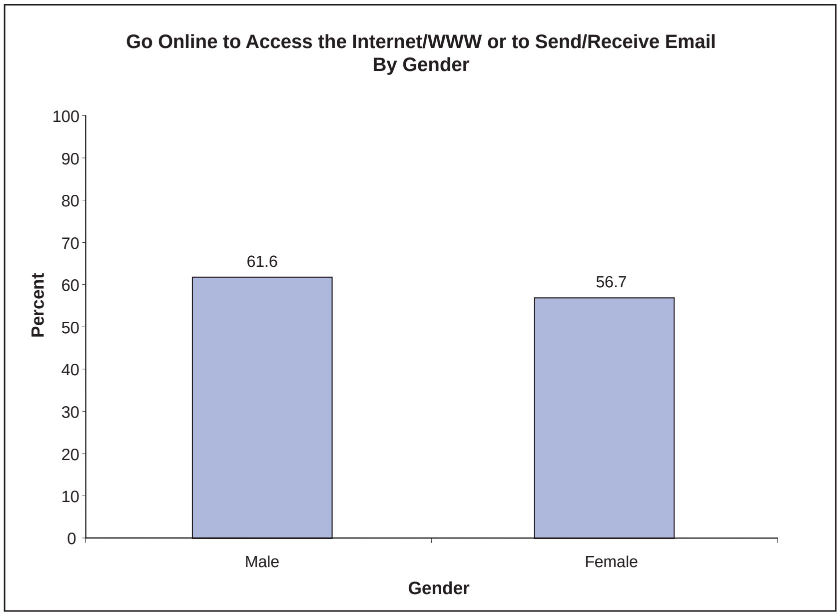


Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database.* Centers for Disease Control and Prevention, January 2004

## 7.2 Gender

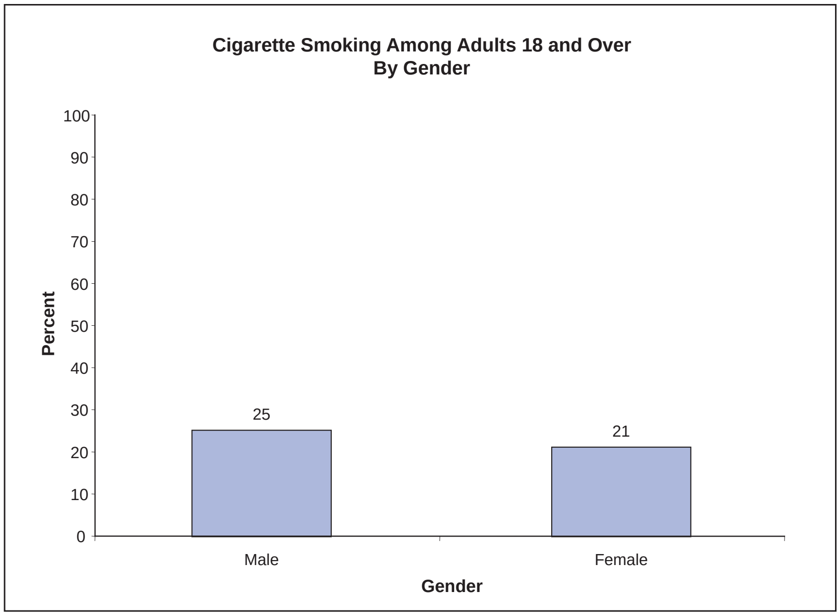
Large differences do not appear to exist between males and females in cigarette smoking (Figure 40). Similarly, differences in Internet use do not appear to differ largely between males and females (Figure 39).

*Figure 39*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 40*

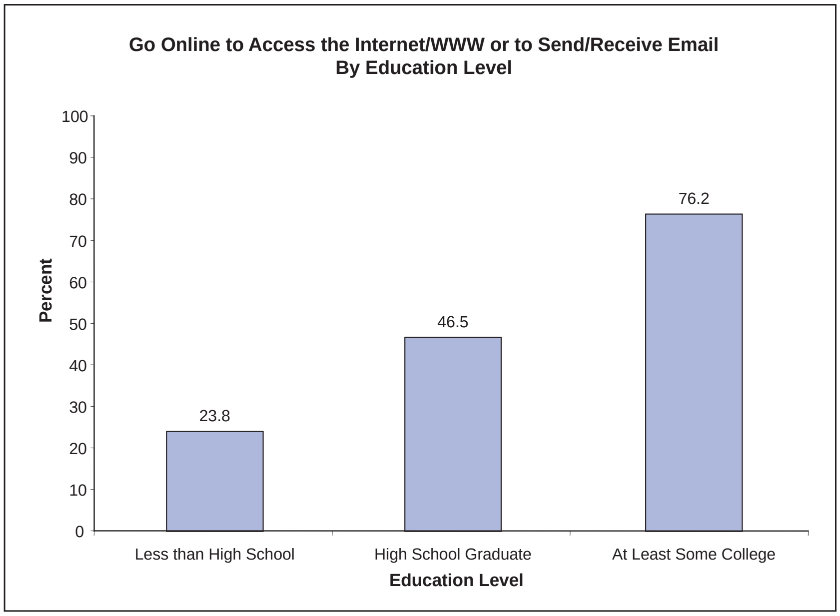


Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database.* Centers for Disease Control and Prevention, January 2004

## 7.3 Education Level

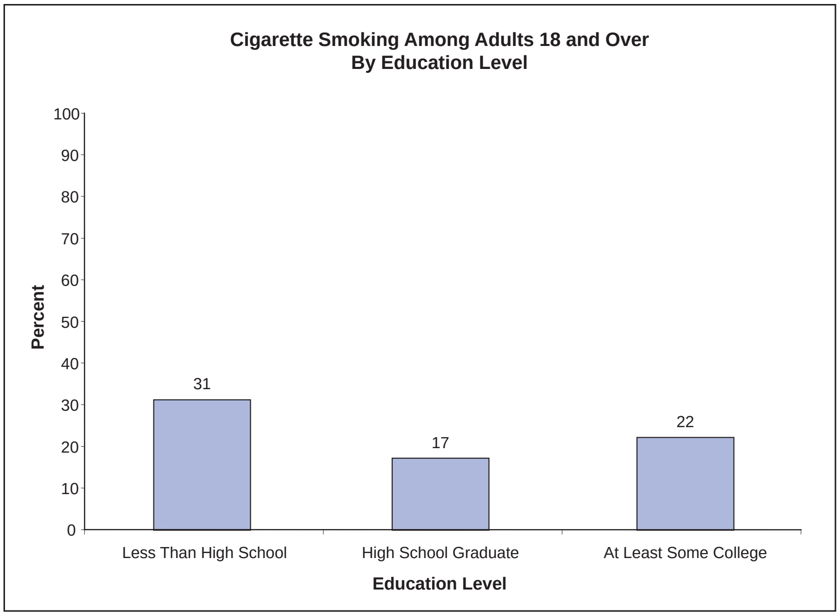
Those with less than a high school education have the highest level of cigarette smoking (Figure 42), but they have the lowest level of Internet use (Figure 41).

*Figure 41*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 42*

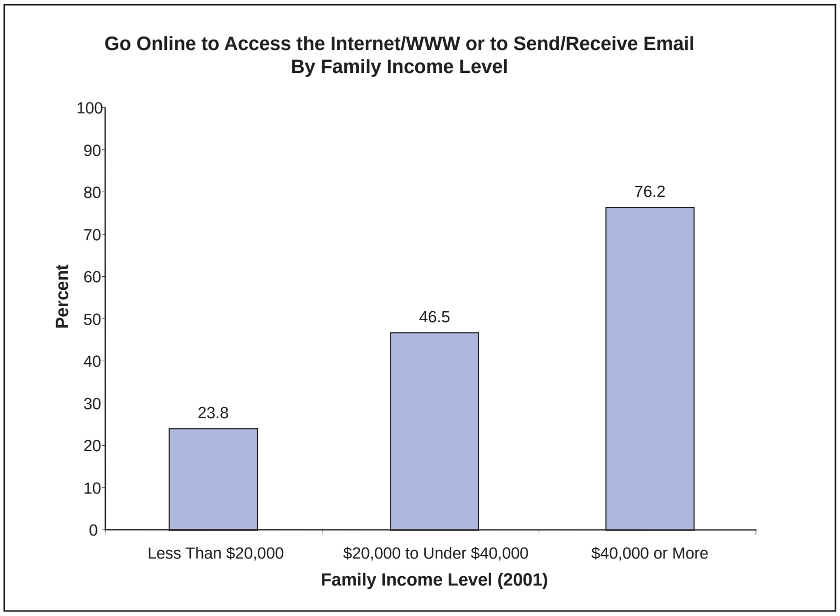


Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database.* Centers for Disease Control and Prevention, January 2004

## 7.4 Family Income Level

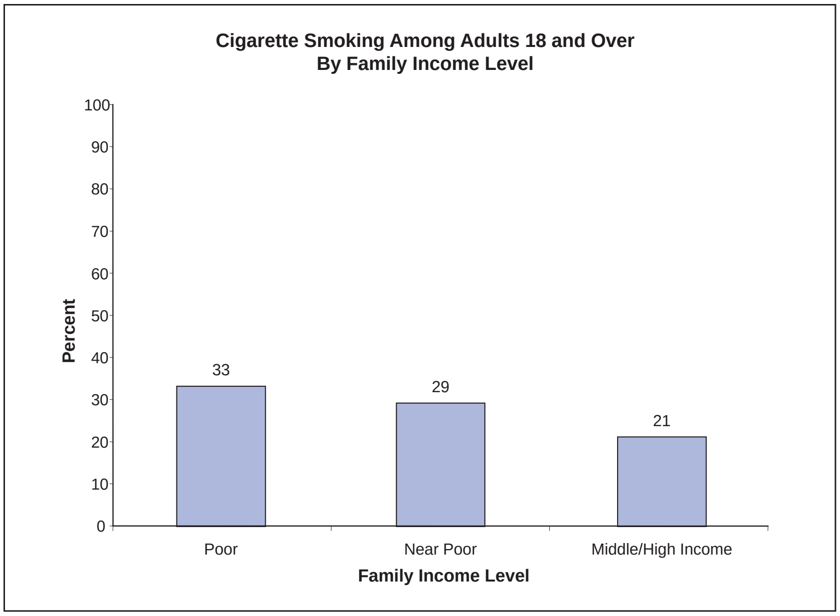
Low-income populations have higher rates of cigarette smoking compared to middle- or high-income populations, yet Internet use is considerably lower for those with lower incomes when compared to those with higher incomes (Figures 43 and 44).

*Figure 43*



Source: Pew Internet & American Life Project's Daily Internet Tracking Survey, 2002–2003

*Figure 44*



Source: CDC Wonder. *DATA2010…the Healthy People 2010 Database*. Centers for Disease Control and Prevention, January 2004

## DATA SOURCES AND METHODOLOGY

### *Pew Internet & American Life Project*

Data from the 2002–2003 Pew Internet & American Life Project's Daily Internet Tracking Survey were used to construct the Internet use profiles presented in the charts. The datasets that were analyzed include all cases of completed surveys aggregated for 2002 (n=25,908) and March through August 2003 (n=20,871).[1] The sample for the survey is a random digit sample of telephone numbers selected from telephone exchanges in the continental United States. Respondents were English-speaking adults older than age 18 and living in the continental United States. (In the most recent Pew Research Center survey conducted in October/November 2005, respondents were given the opportunity to answer an English-language or Spanish-language questionnaire. Of 271 Hispanics, 110 chose the Spanish option and 161 chose English.) Sample data are weighted based on demographic weighting parameters derived from the most recently available U.S. Census Bureau's Current Population Survey. This produces population parameters for the demographic characteristics of adults age 18 or older who live in households that contain a telephone.

Select questions were chosen from the survey instrument to analyze computer/Internet use, Internet activities, locations of access, and the frequency of Internet use from home. For the purposes of this document, the activities of going online to access the Internet and sending or receiving e-mail were used to determine which respondents were Internet users. This classification was based on the respondent pool that answered "yes" to the question, "Do you use a computer at the workplace, home, or anywhere else on at least an occasional basis?" Cross-tabulation of the selected questions by the various population groups was the main method of analysis. In the latest Pew Research Center survey conducted in October/November 2005, Pew used two questions to determine if someone was an Internet user: "Do you use the Internet, at least occasionally?" and "Do you send or receive e-mail, at least occasionally?"

### *DATA2010*

*DATA2010* is an interactive database system developed by the Centers for Disease Control and Prevention's National Center for Health Statistics, Health Promotion Statistics Division, which contains the most recent monitoring data for tracking *Healthy People 2010*. The data are updated quarterly. Data used in this document were obtained from the January 2004 edition.

*DATA2010* also includes a set of measures relevant for tracking progress for the *HealthierUS* initiative. *HealthierUS* is the national initiative to ensure that Americans live longer, better, and healthier lives. The initiative focuses on reducing the burden of disease and addressing lifestyle choices that will foster healthy behaviors through personal and social responsibility.

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[1] The 2003 dataset was only used for data on disability status, as disability status was not included in the 2002 dataset.

Data on the following health topics are presented in this appendix:

- Diabetes
- Obesity
- Asthma
- Heart disease and stroke
- Cancer
- Poor nutrition and physical activity
- Tobacco use

## *Healthy People 2010 Population Group Table*

| ***Healthy People 2010*** **Population Groups** | ***Healthy People 2010*** **Definitions for Population Groups** | **Sample Size From Pew's Daily Tracking Survey** |
|---|---|---|
| **Race and Ethnicity** (Race and ethnicity categories are based on Office of Management and Budget [OMB] guidelines for reporting race and ethnicity. Persons of Hispanic origin may be of any race, and persons in the various race groups may be of any origin.) | | |
| American Indian or Alaska Native | Persons having origins in any of the original people of North and South America (including Central America), and who maintain tribal affiliation or community attachment | 457 |
| Asian or Pacific Islander | Persons having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam | 478 |
| Asian | Persons having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent | — |
| Native Hawaiian and Other Pacific Islander | Persons having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands | — |
| Black or African American | Persons having origins in any of the black racial groups of Africa | 2,995 |
| White | Persons having origins in any of the original peoples of Europe, the Middle East, or North Africa | 20,687 |
| Hispanic or Latino | Persons of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. The term, "Spanish origin," can be used in addition to "Hispanic or Latino." | 2,455 |

| *Healthy People 2010* Population Groups | *Healthy People 2010* Definitions for Population Groups | Sample Size From Pew's Daily Tracking Survey |
|---|---|---|
| Not Hispanic or Latino | — | 23,170 |
| Black or African American | — | 2,752 |
| White | — | 19,177 |
| **Gender** | | |
| Female | — | 12,478 |
| Male | — | 13,430 |
| **Family Income Level** (Poverty status measures family income relative to family size using the poverty thresholds developed by the U.S. Census, which are based on definitions originally developed by the Social Security Administration.) | | |
| Poor | Below the Federal poverty level | — |
| Near poor | 100–199% of the Federal poverty level | — |
| Middle/high income | 200% or more of the Federal poverty level | — |
| **Education Level** (Educational level is typically measured by the number of years of education the individual has completed or by the highest credential received.) | | |
| Less than high school | Persons with less than 12 years of schooling or no high school diploma | 3,637 |
| High school graduate | Persons with either 12 years of schooling, a high school diploma, or GED | 8,267 |
| At least some college | Persons with a high school diploma or GED and 13 or more years of schooling | 13,797 |
| Additional categories included where appropriate | | |
| **Geographic Location** (Urban residence is specified as either residing within or outside a metropolitan statistical area [MSA] or residing within or outside an urbanized area [UA][a] or urban place, as designated by the U.S. Census Bureau.) | | |
| Urban | Living within the boundaries of a UA and the urban portion of places outside a UA that have a decennial population of 2,500 or more | 2,698 |
| Rural | — | 2,338 |

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[a] A UA is an area consisting of a central place(s) and adjacent urban fringe that together have a minimum residential population of at least 50,000 people and generally an overall population density of at least 1,000 people per square mile of land area.

| *Healthy People 2010* Population Groups | *Healthy People 2010* Definitions for Population Groups | Sample Size From Pew's Daily Tracking Survey |
|---|---|---|
| **Health Insurance Status** (Individuals are considered to have health insurance if they are covered by either private or public health plans. Health insurance information applies only to persons younger than 65 years of age. Those 65 and older are considered to be covered by Medicare.) | | |
| Private health insurance | Includes fee-for-service plans, single-service hospital plans, and coverage by health maintenance organizations | — |
| Public health insurance | Includes Medicaid or other public assistance, Aid for Families with Dependent Children (AFDC), Supplemental Security Income (SSI), and military health plan coverage | — |
| Medicare | — | — |
| Medicaid | — | — |
| No health insurance | — | — |
| **Disability Status** (Disability is operationally defined in a number of different ways for program purposes and for analytic and research purposes. For *Healthy People 2010*, disability is primarily defined using information on activity limitation or the use of special equipment.) | | |
| Persons with disabilities or activity limitations | Defined based on information on activity limitation or the use of special equipment | 687 |
| Persons without disabilities or activity limitations | — | 4,229 |
| **Select Populations** | | |
| Age groups | — | — |
| School grade levels | — | — |
| Persons with select medical conditions | — | — |

Source: U.S. Department of Health and Human Services. *Healthy People 2010.* 2nd ed. With understanding and improving health and objectives for improving health. 2 vols. Washington, DC: U.S. Government Printing Office, November 2000.

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