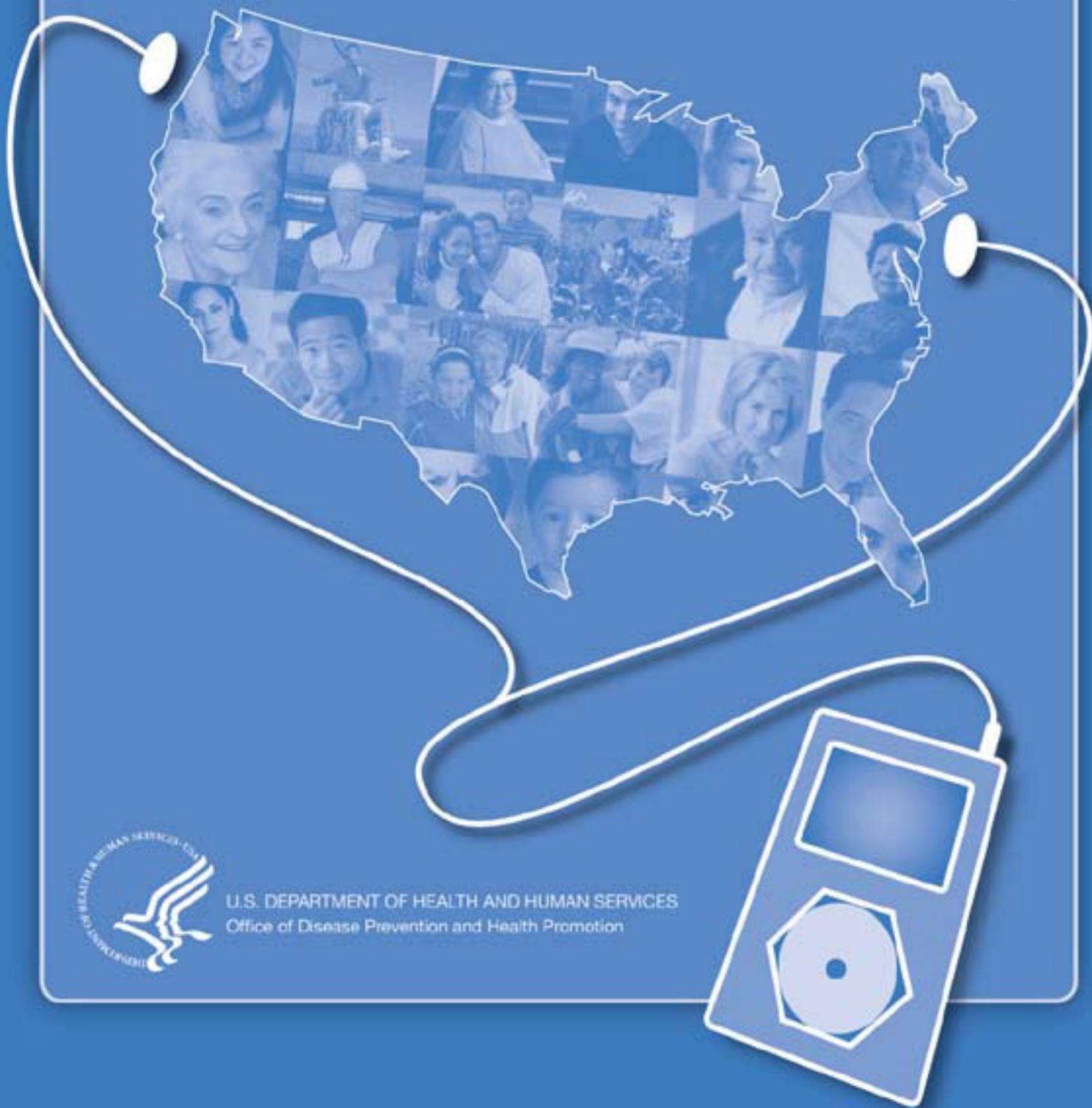


Expanding the

# REACH AND IMPACT of Consumer E-HEALTH TOOLS

*Executive Summary*



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

**EXPANDING THE  
REACH AND IMPACT  
OF CONSUMER  
E-HEALTH TOOLS**

**EXECUTIVE SUMMARY**

**JUNE 2006**



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

## EXECUTIVE SUMMARY

### A Vision of e-Health Benefits for All

The Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services, undertook a study of 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](http://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](http://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](http://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 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](http://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](#) of the full report 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.

# Summary of Chapters

The following is a summary of the chapters in the full report, *Expanding the Reach and Impact of Consumer e-Health Tools*.

## 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 *Wired for Health and Well-Being: The Emergence of Interactive Health Communication* 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](#) of the full report.)

**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](#) of the full report.)

**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](#) of the full report.)

**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](#) of the full report.)

**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](#) of the full report.)

## 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 1](#) 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

*Table 1. Potential e-Health Value Propositions for Major Stakeholders*

Stakeholders	Benefits Sought From Consumer e-Health
Consumers (e.g., patients, informal caregivers, information intermediaries)	<ul style="list-style-type: none"> <li>• Private, 24/7 access to resources</li> <li>• Expanded choice and autonomy</li> <li>• New forms of social support</li> <li>• Possibility of better health</li> <li>• More efficient record management</li> <li>• Lower cost healthcare services</li> <li>• Avoidance of duplication of services</li> </ul>
Consumer advocacy and voluntary health organizations (e.g., AARP, American Cancer Society)	<ul style="list-style-type: none"> <li>• Greater capacity for health management and education for constituents</li> <li>• New communication channels</li> <li>• More efficient service to constituents</li> </ul>
Employers, healthcare purchasers, and third-party payers	<ul style="list-style-type: none"> <li>• Healthier employees more capable of health management</li> <li>• Lower healthcare costs</li> </ul>
Community-based organizations	<ul style="list-style-type: none"> <li>• Constituents with greater capacity for health management and well-being</li> <li>• Healthier communities</li> <li>• Lower cost healthcare services</li> </ul>
Clinicians	<ul style="list-style-type: none"> <li>• Greater efficiency</li> <li>• Better communication</li> <li>• More adherent and satisfied patients</li> </ul>
Healthcare organizations	<ul style="list-style-type: none"> <li>• More patient self-care and health management</li> <li>• Lower administrative costs</li> <li>• Improved quality and patient outcomes</li> </ul>
Public health programs	<ul style="list-style-type: none"> <li>• A healthier population more capable of self-care and less at risk for avoidable disease</li> </ul>
e-Health developers	<ul style="list-style-type: none"> <li>• Sustained use of e-health products</li> <li>• New sources of support for product development and evaluation</li> </ul>
Industry and commerce	<ul style="list-style-type: none"> <li>• New advertising vehicles</li> <li>• Wider markets for products</li> </ul>
Policymakers and funders (public and private)	<ul style="list-style-type: none"> <li>• Effective means of implementing programs and policies</li> <li>• Cost-containment or cost-reduction strategies</li> <li>• Quality improvement strategies</li> </ul>

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.