

## 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.