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

---

[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.